Part Five GENETIC TESTING OF COMPETENT MINORS

1 INTRODUCTION

There is some evidence that minors occasionally request genetic testing.[1] Some seek it on their own behalf, while others do so in conjunction with their parents or guardians. However, there is considerable disagreement as to whether minors should be tested at all, regardless of their competence.

> *A line has been drawn between young people and adults in current discourse surrounding predictive genetic testing. Adults can access such tests with ease, yet the possibility of granting young people similar ease of access incites passionate debate.*[2]

This part of the report is concerned with genetic testing of competent minors at their request. It covers predictive testing, which includes pre-symptomatic and susceptibility testing, and carrier testing.

Arguments opposing genetic testing in competent minors are generally premised on one or both of the following arguments: the consequences of genetic testing may be too harmful to permit minors to give legally effective consent to testing (even if they are competent to consent to other medical procedures); and genetic information and the implications of genetic testing are such that minors cannot competently comprehend them and give effective consent to testing. We have already considered whether there is merit in the view that minors should not be granted access to genetic testing, regardless of competence, by examining the harms and benefits of genetic testing. The limited evidence available regarding harms does not support the view that the consequences of testing would be too harmful. Such evidence as exists suggests not only that there are benefits in testing competent minors, but also that there may be harm in not testing competent minors who for good reason request a genetic test.

We now explore the current law in New Zealand to determine whether it would permit competent minors to consent to genetic testing and whether genetic testing should require special consent conditions. There is no explicit regulation or policy relating to genetic testing of minors in New Zealand. Competent minors can consent and refuse consent to medical treatment and procedures pursuant to section 36(1) of the Care of Children Act (COCA) 2004, *Gillick* as applied in New Zealand and the Code of Health and Disability Services Consumers' Rights 1996. Such evidence as exists with regard to genetic testing of minors does not support the view that genetic testing requires a different regulatory or policy response from that currently in place for competent minors making general medical decisions.

Exploring the issues with regard to competent minors in our existing medical decision-making context not only serves to highlight a few anomalies and concerns

within the current system (particularly in relation to how competence is assessed and section 36(1) of the COCA 2004 is to be interpreted), but also helps to clarify the debate around whether a higher standard of competence is required with respect to consent to genetic testing.

In our view, consent to genetic testing does not require a higher level of competence than consent to medical treatment or procedures relating to other serious conditions. The genetic testing procedure, in terms of medical intervention, is simple (usually a blood test). The genetic information and consequences of a positive or negative result may be more complex; but this is an issue and a challenge for practitioners in terms of information giving, rather than an issue that affects a minor's competence or legal capacity. Because genetic test results can have significant implications for a minor's future, the capacity to understand the short and long-term risks and benefits of testing must be carefully considered. However that is also the case for many other treatments and procedures, such as cancer treatment or organ transplants.

We contend that our existing medico-legal framework already recognises the ability of competent minors to give legally effective consent to genetic testing. We argue that this is the appropriate response because it respects the autonomy of the competent minor and there is limited evidence of actual significant harm caused by genetic testing of competent minors at their own request. Given that the request is only likely to be made when the minor is at risk, harm may in fact ensue from not testing the minor.

We argue that the legal framework for medical decision-making in New Zealand is largely appropriate in its application to genetic testing of competent minors. However, we recommend that, in light of the prevalent discourse focusing on the harms of genetic testing, we implement our own set of guidelines or protocols on genetic testing of minors to clarify and raise awareness of the issues for New Zealand practitioners, parents and society as a whole.

2 GENERAL LEGAL CONTEXT REGARDING COMPETENT MINORS AND GENETIC TESTING

Because of the difficulty in determining a psychosocial benefit, the discourse about genetic testing of minors ultimately tends to focus on who has the right to make the decision and whose right to autonomy is jeopardized.[3]

2.1 Introduction

There is a passionate debate about whether a minor should be allowed to consent to genetic testing. One argument against genetic testing is that the potential consequences are too harmful for minors. We argued in the second section of this report that there is little evidence to support that view and that harms may potentially arise from not testing a competent minor who has requested a genetic test. We concluded that, on the balance of the existing evidence, the potential benefits of testing, particularly when benefits are viewed holistically, appear to outweigh the potential harms when testing is undertaken at the request of a competent minor. In any event, the evidence of harm is not sufficiently strong to persuade us that minors should be denied access to genetic testing.

A second argument against genetic testing of minors is that they lack the competence to consent.

This section focuses on the existing general legal framework relevant to competent minors and decision-making in clinical genetics, and how minors might become aware that they are at risk for a heritable genetic disorder.

2.2 Scenarios in which a minor's ability to consent to or refuse to consent to genetic testing will become relevant

In order to give the following discussion a practical context, it is important to envisage the scenarios in which a minor's ability to consent to or refuse to consent to genetic testing will become relevant – before embarking on a discussion of the regulatory framework within which such decisions must be made.

- A minor might seek genetic testing with the support of parents or legal guardians.
- A minor might seek genetic testing alone, or with a friend or an adult who is not legally entitled to give proxy consent to medical procedures on the minor's behalf. The minor's parents or guardians might be unaware of, or disinterested in, the fact that their child is seeking genetic testing.
- A minor might seek genetic testing against the wishes of parents or guardians.

- A minor might be refusing genetic testing that the parents or guardians want her to undergo.[4]

The legal and professional frameworks, within which genetic testing decisions must be made, will now be discussed.

2.3 Genetic testing of competent minors aged sixteen or seventeen

2.3.1 The COCA 2004

Section 36 of the COCA 2004 governs consent by minors to medical procedures generally. It provides:

> **36 Consent to procedures generally**
>
> (1) A consent, or refusal to consent, to any of the following, if given by a child of or over the age of 16 years, has effect as if the child were of full age:
>
> (a) any donation of blood by the child:
>
> (b) any medical, surgical, or dental treatment or procedure (including a blood transfusion …) to be carried out on the child for the child's benefit by a person professionally qualified to carry it out.

Pursuant to section 36(1) of the COCA 2004, children[5] of or over the age of sixteen (or children who are or have been married or in a civil union or de facto relationship, section 36(2)) can consent or refuse to consent, as if they were of full age, to any medical, surgical or dental treatment or procedure (including a blood transfusion), to be carried out for his or her benefit by a person professionally qualified to carry it out.

2.3.2 Genetic testing: Treatment or procedure?

The right given to sixteen and seventeen-year-olds[6] to make their own medical decisions was significantly broadened by the COCA 2004: the ability to *refuse* to consent, as opposed to merely consent, was not present in the previous provision (section 25(1) of the Guardianship Act 1968); and 'treatments' as well as 'procedures' have been included in the provision, indicating that young adults have rights in respect of a wider range of interventions.[7]

Even if a predictive genetic test for a condition for which there were no beneficial medical interventions available were not considered to be 'medical treatment,' it would fall within the ambit of the category 'medical procedure'. 'Procedure' must be interpreted according to its ordinary meaning, there being no specific definition in the COCA 2004. According to the *Oxford English Dictionary* procedure means 'The fact or manner of proceeding with any action, or in any circumstance or situation; … a series of steps followed in a regular definite order'.[8] Therefore, *prima facie* pursuant

to section 36(1) of the COCA 2004, minors of or over the age of sixteen have the legal right to consent or refuse consent to a genetic test.

However, note the proviso in section 36(1): a sixteen or seventeen-year-old's consent (or refusal to consent) to a medical procedure has effect as if she were of full age if the procedure is to be carried out for her *benefit*. This proviso creates some anomalies.

2.3.3 Interpretation of 'To be carried out on the child for the child's benefit'

The wording of section 36(1) is clear in empowering sixteen and seventeen-year-olds to consent or refuse consent to treatment and procedures for their benefit. Its predecessor, section 25 of the Guardianship Act 1969, was much narrower in scope in that it only permitted sixteen and seventeen-year-olds only to *consent* to treatment for their benefit. It was not clear if they could refuse treatment, whether or not it was for their benefit. The United Kingdom case law has relied on a lack of statutory recognition of a right to refuse consent to override a minor's refusal.[9] But commentators here were of the view that such an interpretation was illogical and undesirable. If sixteen-year-olds were presumed to have the same competence as an adult to consent, they should also have the competence to refuse. Those views were implemented in the COCA 2004. Section 36(1) permits sixteen and seventeen-year-olds to refuse treatment even if the proposed treatment is to the benefit of the minor. The amendment significantly enhances the rights of sixteen and seventeen-year-olds to make health-care decisions.

However, by retaining the proviso relating to 'benefit', section 36 creates an anomaly on a literal reading. The minor would have the right to refuse treatment that is to the minor's benefit, but not the right to refuse treatment that is not to the minor's benefit. This interpretation defeats common sense. Section 5(1) of the Interpretation Act 1999 states that the meaning of an enactment must be ascertained from its text *and in the light of its purpose*. A purposive interpretation of the section suggests that Parliament intended sixteen and seventeen-year-olds to have the same competence as adults in the context of medical decision-making. On that view, the minor would have the right to consent to or refuse treatment, whether it is to the minor's benefit or not. In our view, this is the better interpretation. If our interpretation is incorrect, section 36 leaves a gap in the law governing minors. In that case the common law rules will govern competence to consent.[10]

The 'benefit proviso' in section 36(1) has not been subject to subsequent judicial interpretation. Academic commentary suggests that the proviso is aimed at restricting minors from consenting to non-therapeutic procedures, such as organ donation.[11] Commentary on section 61 of the Crimes Act 1961 (which protects people from criminal responsibility 'for performing with reasonable care and skill any surgical operation upon any person for his *benefit*, if the performance of the operation was reasonable …') is along similar lines.

> *However, s 61 would not justify the doctor in performing an operation which was intended only for the benefit of another person (for example, the removal of the patient's kidneys for transplantation) or one which was intended only to increase medical knowledge.*[12]

Additionally, the inclusion (and lack of definition) of the word 'procedure' in section 36(1) (as opposed to merely treatment) 'could be interpreted to allow a child to consent to medical procedures that need not be directly for the benefit of that child'.[13]

The purposive approach to statutory interpretation of section 36(1) endorses the reading that sixteen or seventeen-year-old minors can legally consent to treatment or a procedure that they believe is for their *own* benefit. The provision is aimed at recognising and respecting the competency and autonomy of sixteen and seventeen-year-olds as if they were of full age.

2.3.4 Meaning of benefit

The word 'benefit' is not defined in the COCA 2004, nor was it discussed during the parliamentary debates on the Care of Children Bill.

If our interpretation is incorrect and minors are indeed only permitted to consent or refuse consent to treatments and procedures that are of benefit to them, then we would argue that 'benefit' should be interpreted widely to include not only physical benefits, but also psychological and emotional benefits, as explained in the second section of this report. It would thus be possible for sixteen and seventeen-year-old minors to consent to pre-symptomatic genetic testing as well as susceptibility testing and carrier testing. As outlined earlier, all of these tests can be beneficial to the minor.

Note that section 36(1) does not restrict a sixteen or seventeen-year-old minor to consenting only to procedures that are in the minor's 'best interests'. Such a qualification on consent would require an overall balancing and assessment of all of the purported benefits and harms and the likelihood of any or all of them resulting from testing. Whilst the phrase 'best interests' is used in other parts of the Act,[14] it is not employed in this section. The term 'benefit' is used, as it is in section 61 of the Crimes Act 1961, in relation to which it has been said:

> *The 'for his benefit' requirement is not expressed in terms of physical benefit alone. It should not be interpreted in a restrictive way …*[15]

The benefit standard is different from the 'best interests' standard, and presumably was used purposefully. Again, taking the purposive approach to interpretation of section 36(1), where there are benefits to genetic testing in a particular case, then a sixteen or seventeen-year-old minor's consent to such testing is as effective as if he or she were of full age. It matters not what those benefits are, or even if some harms

are also attendant – so long as there are benefits. Furthermore, there is no stipulation that the benefit to the minor must be medical.

The term benefit should be interpreted holistically, as the phrase best interests has been interpreted,[16] to include psychological, social and other benefits. The non-medical benefits and harms of the various kinds of genetic tests have been discussed.[17] The evidence for both outcomes is tentative at best, but there appears to be more evidence of benefits arising from genetic testing, particularly on request, than evidence of harms.

If a minor is seeking a genetic test voluntarily and without pressure from others, this *prima facie* indicates that the minor considers that testing will be beneficial. The sixteen or seventeen-year-old minor who consents to a genetic test in these circumstances is exercising autonomy and making personal decisions about life (which is the purpose of the provision). The minor is presumed competent by statute, which should be the end of the inquiry.[18] Regardless, we have argued earlier, in the section on 'Benefits and harms', that allowing a competent person to exercise autonomy and liberty, and make individual choices, is beneficial.

We agree with Skegg's comment that the benefit proviso 'may not be all that significant'.

> *The reference to 'benefit' in section 36(1)(b) is not qualified by 'health', 'bodily', or any such word, so other considerations could be taken into account. Furthermore, in other medico-legal contexts, the concept of 'benefit' has proved extraordinarily malleable.*[19]

2.3.5 Conclusion for genetic testing of sixteen and seventeen-year-olds

In our view, sixteen and seventeen-year-olds have the statutory right to consent or refuse consent to genetic testing by virtue of section 36(1) of the COCA 2004. Even if their rights are confined to treatments *or* procedures that are to their benefit, we conclude that they would still be entitled to seek and consent to genetic testing, because the most recent and extensive evidence (discussed earlier) points towards clear benefits arising from genetic testing of minors on the basis of their own informed consent.

There is clear evidence of clinical benefits attendant upon predictive testing for some disorders for which medical interventions are available e.g. the FAP mutation. There are also benefits to symptomatic genetic testing. Additionally, there are non-medical benefits to carrier testing or predictive testing for disorders for which there are no effective medical interventions (e.g time, knowledge and opportunity to use the genetic information to make decisions and plan for the future).[20]

The issue is a subjective one for the minor to decide, not least because benefits can arise merely from respecting and acting upon a minor's autonomous decision (enhanced autonomy and confidence).

Regardless of the benefits and harms, the significant competence and autonomy of sixteen and seventeen-year-olds requires that they be able to make these decisions for themselves, in accordance with the purpose of the consent provision in section 36(1) of the COCA 2004.

2.4 Genetic testing of competent minors under the age of sixteen

2.4.1 The COCA 2004

While minors of or over the age of sixteen have a statutory right to consent to or refuse medical treatment, the COCA 2004 is silent as to what rights, if any, minors under the age of sixteen have in respect of consenting to medical treatment.

Section 13 of the COCA 2004 indicates that the Act is a code and, except as otherwise expressly provided in the Act, it exists in place of the rules of the common law and of equity as to the guardianship and custody of children. In matters not provided for by the Act, the High Court maintains all the powers in respect of children that it had immediately before the commencement of the Guardianship Act 1968 (on 1 January 1970).

In terms of consent to medical treatment, section 36(5) of the COCA 2004 states that nothing in section 36 affects an enactment or rule of law by or under which, in any circumstances, no consent or no express consent is necessary; or the consent of the child in addition to that of any other person is necessary; or (except for where a child is or has been married or in a civil union or de facto relationship) the consent of any other person instead of the consent of the child is sufficient.

2.4.2 Gillick

The seminal common law judgment on the capacity of persons under the age of sixteen to seek and consent to medical treatment is *Gillick v West Norfolk and Wisbech Area Health Authority and another*,[21] the first authoritative judicial statement recognising children's evolving capacities.

The central issue before the House of Lords was whether a doctor could ever lawfully give contraceptive advice or treatment to a girl under the age of sixteen without a parent's knowledge or consent.

Mrs Gillick had taken exception to a Department of Health and Social Security (DHSS) Health Service notice that stated, or implied, that, at least in certain 'exceptional' cases, a doctor could lawfully prescribe contraception for a girl under

sixteen without her parent's knowledge or consent. The Court of Appeal granted Mrs Gillick declarations to the effect that: the DHSS notice had no authority in law and gave advice which was unlawful, wrong and adversely affected or might affect the welfare of Mrs Gillick's children, and/or Mrs Gillick's rights as parent and custodian of the children, and/or her ability to properly and effectively discharge her duties as parent and custodian; and that no doctor or other professional employed by the Area Health Authority give any contraceptive advice and/or abortion advice and/or treatment to any of Mrs Gillick's children below the age of sixteen without Mrs Gillick's prior knowledge and consent.

The House of Lords (by a majority judgment of 3–2) overturned the Court of Appeal's decision and essentially decided that minors under the age of sixteen could be sufficiently competent in some cases to give valid legal consent to medical treatment. The majority judges reached their conclusions via differing rationales.

Lord Fraser considered the two major questions to be: (1) whether a girl under the age of sixteen had the legal capacity to give valid consent to contraceptive advice and treatment, including medical treatment; and (2) whether giving such advice and treatment to a girl under the age of sixteen without her parents' consent infringed the parents' rights.[22] He answered the first question in the affirmative, there being no statutory bar to recognising the legal capacity of those under the age of sixteen to give valid consent, and not being disposed to 'hold now, for the first time, that a girl aged less than 16 lacks the power to give valid consent to contraceptive advice or treatment, merely on account of her age' (at 409). Lord Fraser stated that it would be

> *verging on the absurd to suggest that a girl or boy aged 15 could not effectively consent, for example, to have a medical examination of some trivial injury to his body or even to have a broken arm set … Provided the patient … is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express them validly and effectively to authorise the medical man to make the examination or give the treatment which he advises (p 409). (Emphasis added.)*

To answer the second question Lord Fraser turned to study parents' rights and duties in respect of medical treatment of their children:

> *… parental rights to control a child do not exist for the benefit of the parent. They exist for the benefit of the child and they are justified only in so far as they enable the parent to perform his duties towards the child … (at 410).*[23]

Lord Fraser surmised that it was 'contrary to the ordinary experience of mankind'[24] to say that a child was under the complete control of his parents until he reached the age of majority, and that upon attaining that age he suddenly acquired independence.

> *In practice most wise parents relax their control gradually as the child develops and encourage him or her to become increasingly independent. Moreover, the degree of parental control actually exercised over a particular child does in practice vary considerably according to his understanding and intelligence and it would … be unrealistic for the courts not to recognise these facts (at 411). (Emphasis added.)*[25]

Lord Fraser appeared to be more concerned with the welfare of minors than with recognising their competence and rights to make or be involved in decisions affecting them. Having established that parents did not have absolute authority over minor children, Fraser LJ determined that the welfare of the particular child was the most important consideration in situations such as these, and that 'there may be circumstances in which a doctor is a better judge of the medical advice and treatment which will conduce to a child's welfare than her parents' (at 412). Lord Fraser was cognizant of the fact that minors were 'often reluctant to confide in their parents about sexual matters' and that the abandonment of confidentiality in such matters 'might cause some of them not to seek professional advice at all' (at 412). The 'only practicable course' was to entrust doctors with the discretion to act in accordance with their views of what was in the best interests of the minor patient; although doctors should always seek to persuade child patients to disclose the situation to their parents (at 413).[26]

Lord Scarman agreed with Lord Fraser but thought it necessary to deliver his own opinion because of the importance of the case (p 414). His Lordship considered that the issue arose 'from the interaction of parental right and a doctor's duty' (p 414). 'The question … is as to the extent and duration of the (parental) right, and the circumstances in which … it can be overridden by the exercise of medical judgment' (at 420).

Lord Scarman stated that while parental rights clearly existed and did not entirely disappear until the child reached the age of majority, the common law had never treated those rights as 'sovereign or beyond review and control'.

> *Nor has our law ever treated the child as other than a person with capacities and rights recognised by law. The principle of the law … is that parental rights are derived from parental duty and exist only so long as they are needed for the protection of the person and property of the child (at 420).*

Lord Scarman's review of the relevant common law highlighted judicial attention to the *understanding* of minors when considering their capacities in various scenarios. His lordship relied upon the same statements (as Lord Fraser had) in Blackstone's Commentaries, *R v D* and *Hewer v Bryant*[27] in reaching his conclusion:

> *… the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give consent valid in law (at 423). (Emphasis added.)*

The rationale for Lord Scarman's conclusion appears to be that minors of 'sufficient understanding and intelligence' can consent to contraceptive advice or treatment on the basis of their own *competence* to give legally effective consent (rather than because not requiring parental consent might be more practical, or in a minor's best interests, as appears to be Lord Fraser's rationale).

The third majority judgment, delivered by Lord Bridge, focuses largely on jurisdictional and procedural issues. With regard to the substantive question of whether a minor under the age of sixteen years can give a legally valid consent to contraceptive treatment his Lordship simply stated that he fully agreed with the reasons expressed by both Lords Fraser and Scarman (p 425).

Lord Templeman delivered the major dissenting judgment.[28] His Lordship framed the question before the House most succinctly: ' … this appeal involves consideration of the independence of a teenager, the powers of a parent and the duties of a doctor. The question is: who has the right to decide whether an unmarried girl under the age of 16 may practice contraception?'

Although Lord Templeman began by stating 'An unmarried girl under the age of 16 does not, in my opinion, possess the power in law to decide for herself to practise contraception' (p 431), his Lordship opined that minors under the age of sixteen could consent to some forms of medical treatment.

> *I accept … that a doctor may lawfully carry out some forms of treatment with the consent of an infant patient and against the opposition of a parent … . The effect of the consent … depends upon the nature of the treatment and the age and understanding of the infant. For example, a doctor with the consent of an intelligent boy or girl of 15 could in my opinion safely remove tonsils or a troublesome appendix (p 432).*

However, Lord Templeman did not consider that girls under the age of sixteen could be competent to consent to contraceptive advice or treatment: ' … any decision on the part of a girl to practise sex and contraception requires not only knowledge of the facts of life and of the dangers of pregnancy and disease but also an understanding of the emotional and other consequences to her family, her male partner and to herself' (p 432).

Templeman, LJ supported his argument by reference to the criminal law provisions that made sexual intercourse with girls under the age of sixteen unlawful. Parliament had deemed that such a girl was not mature enough to consent to sexual intercourse, the potential harms of which contraception was aimed at alleviating; by implication nor could she have the maturity to give valid consent in matters related to contraception (p 431). Lord Templeman's opposition to minors under the age of sixteen giving effective consent to contraceptive advice or treatment was very much focused on the specifics of the issue of sexual activity and contraception: 'the regular, frequent or casual practice of sexual intercourse by a girl or boy under the age of 16 cannot be beneficial to anybody and may cause harm to character and personality' (p 433).

Illuminating the *ratio decidendi* of the *Gillick* decision is made somewhat difficult given the different *foci* in the five judgments. However, the following statement from Lord Scarman appears to best encapsulate what is meant by reference to the *Gillick* principle (in New Zealand at least):[29] a minor under the age of sixteen can give legally effective consent to medical treatment if he or she has 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed' (p 423). This formulation of the principle is supported by the comments of Lord Fraser, the agreement of Lord Bridge with Lords Fraser and Scarman, and the similar comments given by Lord Templeman in his dissenting judgment.[30]

> *It is now beyond dispute that, at common law, capacity to consent to medical treatment … does not depend on someone being above or below any particular age.*[31]

2.4.3 Gillick and procedures and treatment

Does the *Gillick* principle support the right of competent minors to consent to *procedures*, or only treatment? If the *Gillick* principle only applies to treatment and not 'procedures' then, arguably, those under the age of sixteen could not give valid consent to non-therapeutic genetic testing pursuant to *Gillick*.

The intentions of the Law Lords appear to have been relatively disparate. Lord Scarman took a wide approach, advocating the rights of minors to make their own medical decisions when they were of sufficient understanding and intelligence to 'understand fully what is proposed'. However, others of his colleagues (notably Lords Fraser and Templeman) appeared to take a more welfare-focused approach to minors making their own medical decisions. Taking a welfare approach could result in denial of the right of competent minors to consent to medical procedures that are non-therapeutic and not considered to be 'treatment'.

However, on its most general formulation the *Gillick* principle does not restrict the right of competent minors to giving legally effective consent to treatment or

to beneficial procedures only. New Zealand Courts are not bound by the House of Lords' judgment in *Gillick,* although the *Gillick* principle has been used generally to recognise the competence of minors in a wide variety of circumstances.[32] In particular, it was applied in the case of *Re SPO*[33] in which a fifteen-year-old minor was held to have sufficient understanding and intelligence to make his own decision on whether to receive a vaccination, which is a medical procedure rather than a treatment.

The Code of Rights, the United Nations Convention on the Rights of the Child, and the existing practice surrounding children and medical decision-making in New Zealand, support the right of competent minors to make their own medical decisions, whether the decision be about a *procedure* or a treatment.

2.4.4 Gillick competency to consent and to refuse consent

The common law principle derived from *Gillick* is that minors under the age of sixteen may have sufficient competence to give valid legal consent to medical treatment. Such capacity to consent will depend on the 'understanding and intelligence' of the individual minor concerned. It is for health professionals (or in the extreme, the Courts) to assess whether a child is '*Gillick* competent'.

The principle of *Gillick* competency has been somewhat limited subsequently in England and Wales by the English Courts, and minors who might have or indeed who have been *Gillick* competent have had their refusals to consent, overridden. In particular, a couple of English Court of Appeal decisions[34] very firmly stated that whilst minors under the age of sixteen could be competent to consent to certain kinds of medical treatments (pursuant to the *Gillick* principle), they did not have equivalent rights to refuse to consent to treatment.

It has been argued that:

> *In all of the above decisions the court considered the children's wishes and feelings and that they should be given increasing weight as they matured, then overrode them. This means that the notion of Gillick competency is, in many ways, redundant …*[35]

However, *Gillick* competency is far from redundant in the United Kingdom. The principle may have been watered down in England and Wales[36] but the principle of *Gillick* competency to consent still exists and is endorsed and relied upon by the medical and legal communities.[37]

To the extent that they state that minors of or over the age of sixteen can have their refusals of medical treatment overridden by a guardian's consent the English Court of Appeal cases are not applicable to the New Zealand legal context.[38] Section 36(1) of the COCA 2004 provides unambiguous legislative recognition of the right of minors aged sixteen or more to *consent* or *refuse* consent to medical treatments as

if they were of full age. The right to refuse consent to treatment as if one was of full age means that such a right cannot be overridden by a parent (as a person of full age cannot have their consent or refusal overridden by a parent).

Those under the age of sixteen are not presumed competent by statute to give valid consent or refusal to consent.[39] The *Gillick* test was formulated in the context of consent to treatment, not refusal of consent. Some have argued that refusing treatment 'involves a higher order of decision making (McCall-Smith, 1992), with often more serious implications than does consenting to treatment (Pearce, 1994)'.[40] For these reasons some might think it prudent that conferral of a minor's right to refuse treatment be delayed longer than her right to consent.

However, we agree with Elliston that:

> *… to draw a distinction between the ability to consent to treatment and the ability to refuse is quite illogical. As has been said, the right to say yes must carry with it the right to say no.[41] If one is able to weigh up the considerations in order to agree to treatment, surely one is equally capable of weighing up the same considerations even though arriving at a different conclusion? It has been suggested that a difference may lie between consenting and refusing to consent in that consent 'involves the acceptance of an experienced view, refusal rejects that experience – and does so from a position of limited understanding.'[42] While this may be true, the same is also likely to be true where adults are asked to make the same choice. Most patients are likely to know less about the treatment of disease than a qualified doctor. The critical point should surely be whether the patient, whatever their status, is in fact able to understand the risks, benefits and possible outcome of their decision. To assume that no-one under the age of 18 is able to do so, whereas those over 18 are assumed to have this ability, again ignores the individuality of the patient by focusing on the status of minority. …*[43]
>
> *By introducing such additional criteria, the courts are shifting the determination of competence from being a test of a person's ability to undergo a rational decision-making process to one of the ability to make what is, in their view, a rational decision. In other words, the crucial factor is the predicted medical outcome of the minor's decision.*[44] *…*
>
> *This may in part stem from the view that the best interests of children are served by enabling them to 'come to an enjoyment of autonomy'.*[45] *This might seem to be reasonable were it not for the fact that the time when such autonomy may be 'enjoyed' in respect of refusing treatment, is set at the wholly arbitrary age of 18.*[46]

Section 36(1) of the COCA 2004 extends the rights of sixteen and seventeen-year-olds to include the right to refuse consent to medical treatment. The right to refuse

consent was not in the previous Act (section 25, Guardianship Act 1969). The inclusion of the right to refuse procedures or treatment in section 36 suggests that in New Zealand consent and refusal of consent are seen as two sides of the same coin. It may therefore be inferred that if a minor under the age of sixteen is competent to make the relevant medical decision, the minor may consent or refuse consent.

New Zealand's Health and Disability Commissioner has previously argued that there has been much criticism of the finding in the English Court of Appeal case of *Re W (A Minor)*[47] that it was possible to have both a refusal to consent by a competent minor and a contemporaneous valid consent by a guardian. He contended that it would be possible to avoid such a result in New Zealand by health professionals being cautious in their assessment of competency; and where the minor is found to be competent, relying on section 11 of the Bill of Rights, to come to the conclusion that the parents or guardians lose the right to give or withhold consent to treatment of that teenager.[48]

A working group for the Paediatric Society of New Zealand and the Royal Australasian College of Physicians Board of Paediatrics and Child Health also surmised that it was not clear that New Zealand would follow the direction set by *Re W* 'particularly in light of the Code of Health and Disability Services Consumers' Rights'.[49]

2.4.5 Gillick and the COCA 2004 in New Zealand

Does the Care of Children Act 2004 'have the effect, in New Zealand law, of precluding reliance on common law capacity'[50] and hence a minor or health professional's reliance on *Gillick*?

Section 13 of the COCA 2004 indicates that the Act is a Code and has effect in place of the rules of the common law *as to the guardianship and custody of children*, except as otherwise expressly provided in the Act. However,

> *The common law capacity of children to consent to medical (and other) touchings stands entirely apart from 'the rules of the common law and equity as to the guardianship and custody of children'.*[51]

Skegg further contends that section 36 was originally drafted to 'enhance, rather than restrict, minors' capacity to consent to medical treatment'.[52]

Henaghan has argued that section 15 of the COCA 2004[53] preserves common law powers and duties, which *Gillick* turns upon. Thus the reasoning in *Gillick* can be argued to be applicable to New Zealand.[54] Moreover, the codification existed in similar fashion in section 33 of the Guardianship Act 1968 (as did the definition of guardianship in section 3), and many judgments since then have relied upon the principles in *Gillick*.

The Care of Children Act 2004 has chosen not to address the Gillick competent child. … (It) does not rule out the Gillick competent child and therefore it is still possible to act on the consent of a child who is under 16 and who has sufficient knowledge and understanding of the particular decision.[55]

In response to potential argument that the explicit conferral of a right to consent for sixteen-year-olds implies that those under the age of sixteen have no such right:

The presumption that a parent or guardian must give consent for a … child under 16 is not consistent with common law developments or the Code of Health and Disability Services Consumers' Rights which take a capacity-based approach. The majority of legal experts … advised that consent given by a competent child is sufficient.[56]

Additionally, section 16(1)(c) of the COCA 2004 defines the duties, powers, rights and responsibilities of a guardian to include helping the child to determine questions about important matters affecting the child. This provides explicit statutory recognition of the minor child's capacity to determine some important matters autonomously.

While 'there has not been a thorough examination of the issue in the High Court, much less at Court of Appeal or Supreme Court level'[57] *Gillick* has been *referred to* in a broad spectrum of cases in the District Court, Family Court, High Court and the Court of Appeal. For example, the *Gillick* principle has been referred to by judges in the following contexts: protection order proceedings;[58] child support proceedings brought by a seventeen-year-old;[59] Hague Convention cases;[60] religion and medical treatment cases;[61] care and protection proceedings;[62] criminal cases;[63] a case in which a fourteen-year-old did not want an access order granted in favour of her mother;[64] summing up to the jury in a manslaughter/failing to provide the necessaries case;[65] and, most recently, a case involving a fifteen-year-old minor's consent to meningococcal vaccinations.[66]

The House of Lords decided in Gillick … that when a child reaches a sufficient understanding and intelligence to be capable of making up his own mind, parental rights give way to the child's right to make his own decisions. [Judge Ullrich quotes Lord Scarman, p 188]. … This principle has become known as the Gillick principle and has been applied in New Zealand. … I am satisfied in this case that this 14 and now 15-year old boy does have sufficient understanding and intelligence to be capable of making up his own mind on whether he receives the Meningococcal B vaccination. He has received information from the Public Health nurse at his school and has seen videos about the vaccine. He has discussed the matter with a general practitioner. He has also discussed the matter with his older brother who has been vaccinated and with his friends. He has consistently

maintained his view that he wishes to have the vaccination. … I am satisfied that the young man in this case is competent and should be permitted to make his own decision in respect of vaccination. The fact that his mother opposes him receiving this vaccination should not prevent that occurring if he chooses to go ahead.[67]

The Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992 also recognise that:

A child/young person under the age of 16 years may give valid and effective consent, if he or she has a sufficient understanding of the significance of the proposed treatment. This depends on the maturity of the individual child/young person, the effect at the relevant time of the particular disorder, and the seriousness of the matter for decision. If a child/young person under the age of 16 years is able to give consent, the consent of a parent/guardian is not necessary.[68]

Likewise, the New Zealand Medical Association Code of Ethics stipulates that doctors must accept that autonomy of patients remains important in childhood, and that patients be involved 'within the limits of their capacities', in understanding the nature of their problems, the range of possible solutions, as well as the likely benefits, risks, and costs. Doctors must help assist minors to make informed choices.[69]

The Ministry of Health Information for Practitioners regarding Consent in Child and Youth Health states that *Gillick* is 'generally accepted as binding for New Zealand courts' and that the '*Gillick* test is reflected in the Code of Health and Disability Services Consumers' Rights'.[70] (See discussion later.)

We endorse Skegg's conclusion that accepting that the common law capacity of minors is not extirpated by the COCA 2004 'would also have the benefit of avoiding any possible distinction between capacity for the purpose of Code liability[71] and capacity for criminal and tortious liability'.[72]

Given the indecisive and conflicting High Court decisions,[73] *the matter is not entirely free from doubt. Nevertheless, the better view is that minors' common law capacity to consent to medical treatment has not been extinguished by the New Zealand legislation, and that the consent of those under the age of 16 will sometimes be effective in law, be it for the purpose of the criminal law, the law of torts, or the Code of Rights.*[74] *So, too, will the consent of 16- and 17-year-olds, in circumstances not provided for by statute law.*[75]

How competency is actually to be defined and determined will be discussed further below alongside discussion of whether a higher degree of competency is required by minors in order to give a legally valid consent or refusal to consent to genetic testing.

2.4.6 *Summary and conclusion: Gillick*

The notion of *Gillick* competence to consent to medical treatment is applicable in New Zealand despite the fact that it was not incorporated into the COCA 2004. General practice, various legal instruments, and most of the academic writing in the area suggest that the *Gillick* principle is applicable in New Zealand. The House of Lords decision has also often been referred to approvingly by the New Zealand judiciary and the Health and Disability Commissioner. The COCA 2004 does not rule out the possibility of those under the age of sixteen validly consenting to or refusing medical treatment.

The fact that minors of or over the age of sixteen have the right to consent or refuse consent to treatment (pursuant to section 36(1) COCA 2004) indicates that in New Zealand competence to consent entails competence to refuse treatment also. Thus it may be inferred that minors under the age of sixteen can consent or refuse consent to medical procedures or treatment if they have the requisite degree of competence to make the decision. Assuming that a minor under the age of sixteen is *Gillick* competent, the minor can consent or refuse consent to genetic testing. How to define and interpret competency and whether a higher level of competence is required in respect of consenting to genetic testing is discussed later.

2.5 The Code of Health and Disability Services Consumers' Rights 1996 (the Code) and genetic testing of competent minors

The Code of Health and Disability Services Consumers' Rights 1996 (The Code) was established by the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.[76]

The Code applies to *every* health or disability services consumer, regardless of age.[77] The most important right in the Code in the context of competent minors and medical decision-making is right 7(2), which states that:

> *Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.*

There is thus a rebuttable presumption in favour of all consumers, including minors, being competent to make an informed choice and give informed consent to medical 'services', which means 'health services, or disability services, or both, and includes health care procedures.' Even if the *Gillick* principle was not considered applicable to 'procedures', minors are presumed competent to consent to procedures pursuant to the Code.[78]

Age, particularly in respect of young children, can constitute a reasonable ground for believing that a consumer is not competent. For example:

> *In light of Miss A's young age (10 years) and the nature of the decisions (consent to immunisation), there were reasonable grounds for Dr B to believe that she was not competent to make an informed choice and give informed consent (see right 7(2)).*[79]

However, as evidenced by the *Gillick* judgment, it is a minor's degree of 'understanding and intelligence' that determines her competency and not her age.

> *Indeed, the development of law in this area demonstrates a trend away from age-related thresholds, and instead focuses on the competence of the individual child. The Code of Rights reflects this trend. Under the Code, the relevant question is not what is the age at which a child may validly consent to services, but rather whether the level of understanding of a particular child enables him or her to consent to a particular service. There is no blanket answer to this.*[80]

The Code applies to everyone, regardless of age, and reinforces the right of competent minors to make their own medical choices. Even minors who might be presumed to have diminished competency because of their age, retain the right to make choices and give consent to the extent appropriate to their competence (right 7(3)).

The Ministry of Health (which is just one of a number of agencies and authors that have argued that the Code, with its strong emphasis on individual rights, reflects the notions behind *Gillick*[81]) has expressed that the absence of any specified age restrictions in the Code 'is consistent with an approach that emphasises self-determination to the fullest possible extent'.[82]

> *The Gillick test is reflected in the Code … which creates a presumption of competence (right 7(2)) … The Code's presumption of competence, the common law and our increased recognition of children's participation rights (endorsed by the UN Convention on the Rights of the Child) provide clear support for seeking children's consent to their health care and for providing them with information about matters affecting them.*[83]

A health practitioner must judge whether a minor is competent to give informed consent to a particular procedure, based on her maturity and understanding, and the gravity of the procedure.

> *While the views of the parent or carer as to the child's competence may be taken into account, it is the practitioner's responsibility to form an independent judgement on the matter. … there is no particular age at which all children are deemed to be competent to consent to all health and disability support services.*

Under the Code the actual age of the child is not the important question but rather the level of understanding of the child. The fact that the Code applies to all consumers and does not discriminate on grounds of age means that children must be consulted in regard to consent in a manner relevant to their age.[84]

As articulated in the common law, the 'level of ability necessary to consent' to a medical intervention will often differ according to the 'risk or complexity' of the proposed procedure.

Thus while a child of 12 may be competent to consent to the setting of a broken limb, he or she may lack the necessary maturity and understanding to consent to heart surgery. The key under the Code is to consider each case on its own facts and not to lay down blanket rules.[85]

Whilst there have been many complaints made to the Health and Disability Commissioner (HDC) about providers not meeting their duties under the Code in respect of providing information and seeking informed consent, there are very few opinions or case notes dealing specifically with complaints as to treatment of a minor in reliance upon the minor's consent only, without parental consent**.**

A relatively recent case note of the HDC referred to the 'well established "competency based" assessment' in *Gillick* when deciding whether Doctor C and Nurse D had breached the Code by treating a fourteen-year-old boy, Mr B, with a tetanus toxoid immunisation injection for his open wound, without the knowledge or consent of his mother.[86]

… Mr B's ability to consent to receive an immunisation … is not determined on the basis of his age alone. Rather, Dr C was under a duty to consider whether Mr B was able to make an informed choice and give informed consent … The question whether Mr B was competent … is a question of fact. In assessing Mr B's ability or competence, other factors such as his ability to understand that information given to him about the risks of his condition and the consequences of any decision, as well as the relative seriousness of the situation, are all relevant. … Mr B was 14 years old … A young person of that age is well able to understand basic medical information and give consent to a vaccine injection. There is no evidence that Mr B did not understand any of the information … provided to him. … I am satisfied that Mr B was competent to give his informed consent … and did give his informed consent.[87]

Right 7(7) of the Code gives consumers the right to refuse health services and to withdraw consent to services.[88] Thus, pursuant to the Code, a minor has the right to consent or refuse consent to procedures or treatment if she is competent.[89]

According to right 7(1) of the Code services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent.[90] 'Informed consent' means consent freely given, by the health consumer or, where applicable, by any person who is entitled to consent on the health consumer's behalf (clause 4). Consent given by a competent minor only under coercion or duress (perhaps by a parent or other family member) would thus not meet the threshold required for 'informed consent' and would therefore not authorise health professionals to treat a minor in accordance with that consent.

Informed consent is a process, not a single act and its components include: voluntariness, information and competency.[91] In terms of the actual information required in order to facilitate informed consent:

> ***Right 6 Right to be fully informed***
>
> (1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including–
>
> (a) An explanation of his or her condition; and
>
> (b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
>
> (c) Advice of the estimated time within which the services will be provided; and
>
> (d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
>
> (e) Any other information required by legal, professional, ethical, and other relevant standards; and
>
> (f) The results of tests; and
>
> (g) The results of procedures.
>
> (2) Before making a choice[92] or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent. ..
>
> (4) Every consumer has the right to receive, on request, a written summary of information provided.

The criteria for the kind of information required in order for a person to be able to give informed consent are partly objective and partly subjective.[93] The health-care provider must focus on the ability of the consumer to understand the information given.[94] Obtaining truly informed consent is an area of particular concern in genetic testing, given the complexity of genetic information. This is discussed in more detail later.

Related, right 5 provides that: every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided; and every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

Creating an appropriate environment for minors in which to impart information and answer questions about medical decisions

> *… might include one-on-one or group discussions in which appropriate time is allowed for questions to be asked, and honest and accurate answers given. It may also involve using culturally appropriate methods of communication; plain language rather than medical jargon; written or visual explanations; and diagrams, toys or videos. The involvement of family, whānau or other support persons may often be of assistance to aid understanding.*[95]

Right 8 of the Code gives every consumer the right to have one or more support persons of her choice present.[96] Adolescent minors might prefer a friend or adult outside her family to as a support person. This might be particularly so in the genetic testing context when the information revealed by the test may reveal information about other family members' risk status.

The Code, like *Gillick*, gives competent minors of any age the right to make an informed choice and give informed consent (or refuse consent) to genetic testing. Genetic information and the testing process and its implications must be explained to minors in a manner and language which they can understand.

2.6 New Zealand Bill Of Rights Act 1990 and genetic testing of minors

The New Zealand Bill of Rights Act 1990 (NZBORA) applies only to acts done by: (a) the legislative, executive, or judicial branches of the government; or (b) any person or body in the performance of any public function, power, or duty conferred or imposed by or pursuant to law (section 3). Organisations operating in different spheres of activity may be subject to the NZBORA as a result of applying the public function test (section 3(b)) e.g. District Health Boards and Medical Councils.[97]

Subject to section 4,[98] the rights and freedoms in the NZBORA are subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society (section 5). And, wherever an enactment can be given a meaning that is consistent with the rights and freedoms contained in the NZBORA, that meaning shall be preferred to any other meaning (section 6). 'Section 6 is designed to avoid a situation envisaged by section 4.'[99]

Section 11 of the NZBORA affirms the right to refuse medical treatment. Everybody has the rights in the NZBORA, regardless of age. However, pursuant to the ruling in *Re S*[100] a person must be competent to rely on her section 11 right to refuse medical treatment.[101] The NZBORA does not stipulate criteria for assessing competence in terms of the right to refuse. In *Re S* Barker J implied that competence was related to appreciating the significance of the relevant treatment.[102] Thus the *Gillick* principle appears to apply to the section 11 right to refuse treatment.[103]

The HDC has previously argued that pursuant to *Gillick* and section 11 of the NZBORA, if a young person under the age of sixteen is mature enough to refuse consent to a health-care procedure then that refusal is fully effective (provided it was not coerced of course) and cannot be overridden by the wishes of parents or guardians.[104]

The Ministry of Justice (MOJ) *Guidelines on the New Zealand Bill of Rights Act 1990* acknowledge, in line with the Code, that:

> *every person of diminished competence has the right to grant informed consent to or to refuse treatment to the extent appropriate to the person's level of competence.*[105]

The right to refuse treatment can be limited only to the extent necessary to serve the specific purpose of the limitation, and moreover 'limitations to the application of section 11 should be set out explicitly in statute and will be read strictly'.[106] According to the *Guidelines* 'if Parliament wishes to override basic rights, it needs to do so by using clear and unambiguous language'.[107] Neither the COCA 2004 nor any other statute explicitly limits the right of a minor under the age of sixteen to refuse medical treatment.[108]

Consequently, it would appear that competent minors under the age of sixteen can rely on their section 11 right to refuse treatment. Section 36(1) of the COCA 2004 is to be interpreted consistently with the rights contained in the NZBORA. Therefore, it should not be interpreted as implicitly limiting the right of those under the age of sixteen to refuse treatment.[109] Additionally, where health professionals or health boards are exercising a 'public function' (section 3(b) NZBORA) and are faced with discretion as to a course of action (such as whether or not to test a competent fourteen-year-old who refuses to consent to predictive testing), 'the person exercising the discretion needs to exercise that authority in a way that is consistent with the Bill of Rights Act'.[110] On a simple analysis, where there are no other competing rights or clear statutory rules, this would mean respecting the minor's right to refuse treatment.

According to the MOJ the right to refuse medical treatment extends to 'all forms of health care and medical intervention' and 'serves to maintain a person's bodily

integrity, and human dignity'.[111] A person has a right to refuse treatment even if the decision may be considered to be irrational, objectively medically unsound or contrary their best interests.[112] The right to refuse medical treatment, on this formulation, clearly extends to the right to refuse a genetic test.

Competent minors (whether presumed competent by statute, or *Gillick* competent) can rely upon section 11 of the NZBORA to refuse consent to a genetic test.

2.7 The United Nations Convention On The Rights Of The Child (UNCROC) and genetic testing of minors

The United Nations Convention on the Rights of the Child (UNCROC) was adopted by the United Nations General Assembly in 1989. It is the most widely ratified human rights convention in the world, unratified by just two countries.[113]

Many of UNCROC's fifty-four articles are relevant in the context of medical-decision-making and children, both with regard to adults' responsibilities to act in children's best interests, and also with regard to the need to let children participate in decisions affecting them.[114]

Article 1 defines a child as every human below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier.

Article 3 requires adherence to the best interests of the child as a primary consideration in all public actions concerning children, and that States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her guardians. Note that the MOH urges caution that the 'best interests' principle is not used to indiscriminately override the wishes and interests expressed by children pursuant to the other articles of the Convention.

> *These can best be protected by ensuring that children are well informed to the level of their understanding and in ways which enhance that understanding, and that they are listened to and have their views taken seriously.*[115]

This is relevant in terms of genetic testing and competent minors: a competent minor's request for a genetic test should not be overridden on the basis that the test may not be in her best interests.

Article 5 requires respect for the responsibilities, rights and duties of parents (or others legally responsible for the child) to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognised. Recognising the right of a competent minor to consent to a medical procedure does not necessarily mean completely ignoring family

input: it is natural for families to have input into a decision regarding a heritable genetic condition, and many competent minors will want this involvement.

Article 12 is often referred to as the bedrock of UNCROC:[116]

> *States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.*

Minors are clearly capable of forming their own views on a variety of matters and many of them are also competent to make their own medical decisions. Article 12 underscores the *Gillick* principle and the Code of Rights in insisting that minors' views be given due weight in accordance with their age and maturity.

Article 24 calls upon States Parties to recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Arguably this article supports the right of competent minors to seek genetic testing so that they may enjoy the highest attainable standard of health: predictive testing might afford them an early opportunity for surveillance, prophylaxis, and interventions.

Further, States Parties shall strive to ensure that no child is deprived of the right of access to health care services. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures to combat disease, including within the framework of primary health care, through, *inter alia*, the application of readily available technology; and to develop preventative health care, guidance for parents and family planning education and services. These explicit references to the application of readily available technology to assist in combating disease, and the development of preventative health care, further support the right of competent minors to access genetic testing technology.

The United Nations Committee on the Rights of the Child has recently stated that children should themselves be included from an early age in activities promoting a healthy and disease-preventing lifestyle.[117] Similarly, the New Zealand MOH has stated that article 24 should also guide how matters of consent in relation to children are approached. The ways in which informed consent of children and/or parents and families/whānau is sought, and decisions about treatment of children are made 'should enhance and not inhibit the child's opportunity to get the best health care available for their particular circumstance'.[118]

Many of the UNCROC Articles expressly require assessment of the particular child's age and/or maturity when decision-making in certain areas, reflecting the familiar concepts of evolving capacity and different rates of maturation and development

amongst different children (as promoted in *Gillick* and elsewhere).[119] Article 12 is key in this respect (see earlier discussion).

Despite being a Schedule to the Children's Commissioner Act 2003, UNCROC has not been incorporated into New Zealand law and cannot be directly enforced through the New Zealand Courts.[120] However, there are many valid and strong incentives, policies and statements in place to encourage compliance with UNCROC.[121]

UNCROC has been judicially considered in New Zealand in *Tavita v Minister of Immigration* [1994] 2 NZLR 257, 266:

> *… the United Nations Human Rights Committee is in a sense part of this country's judicial structure, in that individuals subject to New Zealand jurisdiction have direct rights of recourse to it. A failure to give practical effect to international instruments to which New Zealand is a party may attract criticism. Legitimate criticism could extend to the New Zealand Courts if they were to accept the argument that, because a domestic statute giving discretionary powers in general terms does not mention international human rights norms or obligations, the executive is necessarily free to ignore them.*

Judge Ullrich also referred to article 12 of UNCROC in *Re SPO* when discussing the *Gillick* principle:

> *That principle is consistent with the UN Convention on the Rights of the Child which gives children the right to express their views in respect of any decision that affects them and to have their views taken into account by decision makers.*[122]

Several of UNCROC's articles support the right of competent minors to consent or refuse consent to genetic testing in accordance with their level of competency or maturity.

2.8 Comments on New Zealand's general legal context regarding genetic testing and competent minors

The legal framework outlined earlier in respect of competent minors and medical decision-making lends support to the argument that competent minors in New Zealand have the right to give informed consent or refuse consent to genetic testing.

Minors of or over the age of sixteen have the statutory right to consent or refuse consent to genetic testing by virtue of section 36(1) of the COCA 2004. Even if their rights are confined to treatments or procedures that are to their benefit, we conclude that they would still be entitled to consent to genetic testing, because the most recent and extensive evidence (discussed earlier) points towards clear benefits arising from genetic testing of minors on the basis of their own informed consent.

Minors under the age of sixteen are not covered by section 36(1) of the COCA 2004. However, if they are competent they can also make medical decisions on their own behalf, pursuant to *Gillick*, the Code of Health and Disability Services Consumers' Rights, and UNCROC. The right of minors under the age of sixteen to refuse consent has been more controversial in the past. However, *Gillick*, the Code of Rights, the NZBORA and the equal treatment of the right to consent and the right to refuse in section 36(1) of the COCA 2004 all support the right of a competent minor under the age of sixteen to refuse consent to medical procedures or treatment.

Competent minors of any age in New Zealand can give legally effective informed consent, or refuse to consent, to genetic testing.

We next examine the question of whether genetic testing decisions require a higher degree of competence than other medical decisions, and how a minor's competence can be assessed.

3 COMPETENCE AND GENETIC TESTING OF MINORS

From the perspective of genetic screening, for doctors to proceed on a young person's request would seem to require a finding of a high level of maturity, given that the nature and consequences of screening are much more complex than decisions involving a young person's desire to avoid an unwanted pregnancy.[123]

As discussed earlier, minors who have not yet reached the statutory age of consent to medical treatment (sixteen, section 36(1), COCA 2004) can consent and refuse consent to medical treatments or procedures, including predictive or carrier testing, when they are competent to do so. But what does competence mean in this context, and how can it be assessed? Should a greater degree of competence be required by minors requesting or refusing genetic tests because of the complexity of genetic information, and the far-reaching consequences for the adolescent's future well-being and lifestyle?

3.1 What is competence?

Common definitions of 'competent' (e.g. 'having requisite or adequate ability or qualities' or being 'legally qualified or adequate'[124]) are inadequate to describe what is meant by competence in the medico-legal sense.

Legally, competence or legal capacity[125] can be defined in two ways in respect of minors:

1. *Status based competence e.g. section 36(1) of the COCA 2004 gives minors of or over the age of sixteen the right to consent or refuse consent to medical treatment or procedures as if they were of full age: they are statutorily presumed competent to make their own health care decisions on the basis of their age. (This presumption of competence can be rebutted, as it can with any adult, by showing that the minor lacks the required mental or physical capacity. But the minor's competence cannot be denied solely on the basis of age.)*
2. *'Maturity' based (or functional) competence, by which the individual minor's maturity and understanding is assessed to decide whether or not he or she is competent to make her own health care decisions. This was the approach to competency pioneered in Gillick.*[126]

The second form of competence is of the most interest in this section, given that the first is relatively straightforward and has already been discussed earlier.[127]

3.2 The connection between competence and autonomy

Respect for autonomy is the fundamental reason for allowing competent persons to make their own decisions.

> *The treatment choices of competent adults should be respected … provided that the choice is made with an understanding of the probable consequences. … The primary justification for this is respect for the autonomy of persons – their rights of self-determination. This can be defended as a basic right, or by appeal to claims that an ordinary adult, when informed about the options available, knows best what actions fit their own value system and hence best meet their overall needs.*[128]

The same theory applies to competent minors – respecting their choices respects their autonomy to make their own decisions about their lives. Indeed, it is often argued that allowing minors to exercise their autonomy and make their own decisions enhances their ability to do so, and also their competence.[129]

> *Another reason for listening to children is that they are not well-served by being voiceless until the age of majority. They do not emerge from a cocoon at age 18 with full blown decision-making capacity; rather their abilities to make good choices must be developed over time, a process that requires practice.*[130]

> *… permitting minors to exercise their right to make treatment decisions may actually assist them in 'developing decision-making competence with respect to legal issues and life choices, enabling them gradually to assume adult responsibilities'.*[131]

Recognising that competence is linked with autonomy and self-determination assists in assessing competence.

3.3 The connection between competence and informed consent

Pursuant to the Code, health and disability services can be 'provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise'.[132]

Informed consent is only legally effective when it is voluntary; informed; and given by a competent person.[133] A minor cannot give legally effective informed consent unless competent to do so, and consent is given voluntarily. Being judged competent (whether statutorily or on the basis of maturity) is therefore vital in order for a minor to exercise her autonomy in relation to medical decisions, including decisions about genetic testing.

3.3.1 Voluntariness

Consent given by a competent minor only under coercion or duress (perhaps by a parent or other family member) would not meet the threshold required for 'informed consent' and would therefore not authorise health professionals to treat a minor in accordance with that consent.

Genetic testing for heritable disorders may raise more issues around voluntariness and the possibility of family pressure or coercion to have a test, than do other medical tests for non-heritable disorders. The fact that other members of the family suffer from the heritable condition creates an inextricable link between their genetic relationships and their emotional relationships,[134] and may increase their desire to find out the genetic status of other family members (whether for altruistic or other motives). As outlined in the section on genetic testing of children too young to give their own informed consent, parents may wish to have their children tested for a number of reasons. Children or adolescents may be particularly susceptible to family pressure for testing.

However, recognising the competence of a minor to consent to a medical procedure does not mean ignoring or discouraging family input: it is natural for families to have input into the decision.

> *But the emphasis in autonomy goes too far if it means that the mature adolescent's decision must be made entirely on her own before it [sic] entitled to any weight. Family members often influence each other, and parents, in particular, influence their children. We generally would and should be concerned about the adolescent who is making these decisions without the input of his or her family. Thus, in*

attempting to decide whether the teenager's views should tip the balance in favor of testing, the clinician should attempt only to determine whether the adolescent has been very strongly pressured, is in fact ambivalent about, or even opposes testing.[135]

Many adults feel ambivalent about tests for serious conditions, and undertake them partly to inform their relatives. So to look for complete conviction and freedom from family pressures in the child would be as unrealistic as to expect this in all adults. It is a question of a reasonable balance between the child deciding as in individual and as a member of a family, and this will not always be easy to discern.[136]

Additionally, it has been argued that 'Failure to provide adequate time or facilities to receive and reflect on information may be coercive, even if unintentionally so'.[137] As well as the right to be free from coercion (right 2), recall that right 5 of the Code stipulates that 'Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively'. Thus health professionals must provide an adequate environment in which the minor can communicate honestly and effectively, without feeling coerced.

3.3.2 Information

[There are] … two, often confused, elements inherent in the notion of 'informed consent' at common law. One aspect concerns information disclosure and the quality of the information imparted. The second concerns actual consent and the requirements of capacity (or competence) and voluntariness.[138]

All health and disability services consumers have the right to be fully informed, whether or not they will be giving consent on their own behalf. Information giving is separate from consent: even if a minor is not competent to give a valid consent, she has a right to receive appropriate information.[139]

The information that every health consumer is entitled to (stipulated in right 6 of the Code) gives an indication of what kinds of information a person needs to understand in order to be competent to give informed consent:

Right 6 Right to be fully informed

(1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including–

(a) An explanation of his or her condition; and

(b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and

(c) Advice of the estimated time within which the services will be provided; and

(d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and

(e) Any other information required by legal, professional, ethical, and other relevant standards; and

(f) The results of tests; and

(g) The results of procedures. …

(2) … the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.

However, note that competence concerns the *ability to* understand and cannot be exactly equated to the same level of understanding required in order to give informed consent, in that *actual* understanding and the giving of informed consent may very much depend upon the information given by the health professional and the manner in which is it given:

> *It is incumbent on health professionals to provide the child or young person with all relevant information, and to ensure as far as possible that she or he has sufficient understanding on which to make a decision. (Rights 1,5,6 and 7 of the Code of Health and Disability Services Consumers' Rights.)*[140]

> *It would be an entirely 'unsatisfactory state of the law if a doctor could by controlling the information given to a patient thereby grant or deny her competence'.*[141]

Thus a minor can be competent without being in a position to give informed consent, but cannot give informed consent without being competent.

Information must be given to minors in a way that they can understand.[142] Right 5 of the Code provides that: every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided; and every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

> *Assessments of competence usually attend wholly to the child's capacities. Yet the context also needs to be assessed. The competence of most people depends in part on how clearly they are informed by health professionals, and how much their discretion and independence are respected by all concerned. Besides relationships between the individuals, the more general social context affects competence, such as how far experts understand the condition and the relevant testing or treatment, how new or risky the treatment is, how much time and space is allowed … for*

quiet discussion, the beliefs held by the relevant adults about children's abilities, and many other factors.[143]

Creating an appropriate environment for minors in which to impart information and answer questions about medical decisions might include one-on-one discussions

in which appropriate time is allowed for questions to be asked, and honest and accurate answers given. It may also involve using … plain language rather than medical jargon; written or visual explanations; and diagrams … or videos. The involvement of family, whānau or other support persons may often be of assistance to aid understanding.[144]

3.4 Does genetic information make a difference?

Genetic susceptibility testing … may present particular challenges to the informed consent process because of the probabilistic nature of genetic information, the impact of genetic information on an entire family, and children's incomplete or inaccurate understanding of heredity and the disease in their family.[145]

3.4.1 Uncertainty of genetic information

There is a great deal of residual uncertainty regarding the interpretation of predictive genetic test results. When genetic mutations are not fully penetrant, and only indicate susceptibility to a disorder, the risk of developing the associated disorder may vary according to a number of factors e.g. the particular gene(s)/genetic variation(s) in question; the total genetic environment;[146] the family history; and environmental factors. Further factors that might affect a person's likelihood of getting a particular disorder remain unknown.

Research into how adults make decisions relating to genetic risk indicates that decision-making is not done on normative logical information-processing grounds: 'decisions are subject to the simplified short-cuts and biases typical of judgements under uncertainty'.[147]

…evidence is accumulating that we have limited abilities to process information, especially in situations of uncertainty when one is required to estimate and interpret probabilities correctly. Some researchers have pointed out that individuals act particularly irrationally when the probabilities of specific outcomes are very low…[148]

Thus Binedell suggests that when more is known about the actual decision-making processes of adults, there may be 'a lesser gap in competence between adults, adolescents and children than current theory suggests'.[149]

Even if a genetic mutation is predictive or fully penetrant, the genetic test results cannot always, at least at this stage, predict how severe the expressivity of the disorder will be in the particular person tested. It is very difficult to predict how mild or how severe the disorder will present in the person tested. Additionally, there are no guarantees as to the age of onset of any of these types of conditions. These issues arise in the context of genetic testing of adults also; they are not unique to minors. Health professionals need to manage the explanation of genetic test results and genetic information that may contain many uncertainties. Explaining the uncertainties of the results and the information forms part of their obligations pursuant to the Code, to ensure that consumers understand the benefits and costs of each option, and the test results.

3.4.2 Complexity

> *It is far harder to explain severe preventative treatment than to explain treatment intended to alleviate or cure problems which the child is already experiencing.*[150]

The complexity of genetic information and the incomplete understanding of genetics create challenges in terms of the information-giving component of informed consent. Genetics is a highly specialised branch of medical science, not well understood even by health professionals outside of the speciality,[151] let alone the general public. Ensuring that minors and families understand not just the clinical but also the ethical and potentially social and legal consequences of having a test for a genetic disorder is of vital importance.

The fact that genetic information might be more complex than other types of health information means that health professionals need to take great care in explaining the information in a form, language and manner that minors can understand. They must focus on the ability of the minor to understand.

Minors can be given sufficient information via a variety of methods to enable them to make an informed choice about genetic testing. They do not need lectures in medical genetics or inheritance, just as adults are not expected to understand such complexities when they seek testing. Some intelligent minors, in particular, will have no greater difficulty understanding the basic genetics of their condition, and its implications, than less intelligent adults would have. The complexity of the genetic information simply provides challenge to professionals to meet their obligations under the Code and convey the information in a manner and form that minors will be able to understand. If medical genetics could not be translated into a relatively easily understandable format, genetic testing, even of adults, could never take place on the basis of informed consent. The format in which genetic information is conveyed to adults simply needs to be adapted to be more user-friendly for minors, whilst retaining its accuracy.

The consequences of genetic information may be more complex than other medical information, given its ability to predict the future health of an asymptomatic individual, with varying degrees of certainty. Part of informing minors adequately before they make a decision about testing will include informing them about the potential uses of their genetic information by third parties.[152] Adolescents will generally be capable of understanding this type of information, but may never have had cause to give any of these issues much thought.

> *If one were going to live to 75, it might be prudent to invest time in long term projects, defer child bearing until one's career was established, put money aside for retirement, and so on. If this kind of information is of value to adults, why is it not also of value to children?*[153]

3.4.3 Evidence of minors' understanding of genetic information

In a study aimed at assessing adolescents' attitudes towards genetic testing, Harel et al.[154] found that:

- High school students with a mean age of 17 ± 1 years with a family history of breast cancer or high cholesterol were significantly more willing to have predictive testing for a familial breast cancer or hypercholesterolaemia (high blood cholesterol) than students without a family history. Thus students clearly understood that a family history of a heritable genetic mutation put them at greater risk for developing the relevant condition themselves. Likewise, students in the ethnic risk groups for Tay-Sachs disease were significantly more willing to be tested than those who were not in the high risk groups.[155]
- The majority of students surveyed also indicated that they would respond to a potential finding of high cholesterol, as a result of a hypercholesterolaemia test, by changing their diet and increasing their physical activity. Girls who wished to be tested for a familial breast cancer mutation stated that if they received a positive result they would submit to frequent breast examinations and to early mammograms. Both of these outcomes indicate that the students comprehended the implications of the genetic test result.[156]
- Regardless, of whether or not the students would actually go through with genetic testing, if offered, they understood that they were at increased risk and what measures could be taken after a positive test result to manage or reduce the increased risk.[157]

Evaluation of an Australian programme of Tay-Sachs disease and cystic fibrosis carrier screening of 629 students (of a possible 817, 77 per cent) between the ages of fifteen to seventeen years in four private Jewish high schools in Sydney in the late 1990s, found that 99 per cent of the students who chose to participate in the

programme had good knowledge to enable informed consent (after education and a one on one interview session). Additionally, students appeared to understand the potential use of the knowledge and indicated their intentions to use the knowledge rationally in future reproductive decisions.[158] Three to six years later, there was a high retention of knowledge.[159]

Further research on the Montreal Tay-Sachs carrier screening programme suggested that many minors can effectively use genetic information attained during high school years in later reproductive decisions.

> *This analysis shows no negative effects of knowledge of carrier status, and demonstrates that adolescents both remember information regarding their carrier status and use it in an appropriate, mature manner.*[160]

The minors studied by Michie et al. (discussed earlier in the 'Benefits and harms' section) understood the meaning of their positive FAP test results: minors with positive results perceived a higher change of getting polyposis, worried more about that chance and were more threatened by their test results than those who received negative results. There was no difference between minors and adults in how bad they considered polyposis to be, or how bad they thought it would be if they developed it.[161]

Many comments made by the young people that Duncan interviewed (discussed earlier) also indicate understanding of the implications of the genetic information that testing would reveal. For example:

> *I wanted to plan because, you know, what sort of work I'm going to get into, if I want to be a lawyer or a copper or whatever, a factory worker, it doesn't matter you know, but eventually it would have started affecting my work.*[162]

> *I was thinking of going into the airforce but I can't do that now … I've been thinking about being a sports teacher.*[163]

In a study of parents' and children's attitudes toward the enrolment of minors in genetic susceptibility research, Bernhardt et al found that while minors (aged between ten and seventeen years) were initially immediately agreeable to genetic testing and saw few risks (when such was undertaken with a saliva sample, rather than a blood sample) they began to identify the risks of testing as they were talked through the implications.[164] They were encouraged to personalise the implications.

> *Children at risk for heart disease perceived a benefit of being told they had a positive genetic test result because they could then do something to prevent heart disease, such as exercising more, eating better, or losing weight, even if they were already engaged in risk reduction behaviors … Girls at risk for breast cancer would do something to detect breast cancer early.*[165]

Many of the minors at risk for heart disease or breast cancer also wanted to know whether they were at increased risk so that they could psychologically prepare for a diagnosis, and gain some control over aspects of their lives.[166]

Minors began to identify potential harms of testing when the interviewer asked them whether they would want their test results. Around a quarter of the thirty-seven minors interviewed indicated that they would worry if they received a positive test result. Others thought that knowledge would be better than uncertainty, even if they did worry.

Only two of the minors from families at risk for heart disease would not want their results, compared to six from families at risk for breast cancer: children were less likely to want their results if they thought that the condition could not be prevented. Other minors suggested that they would not want their test results if they indicated a probability rather than certainty that they would develop the disorder: they would not want to worry unnecessarily, or to be caught off-guard.

> *Children also expressed many concerns about the privacy of their test results and felt that they should have control over who knew their results.*[167]

Except for one minor who indicated that she would not want anyone to know, all of the children said that they would want their parents and doctors to know their results. Almost half of the children (eighteen of the thirty-seven) would want other adult relatives to know their results, and half would tell at least one friend, with several indicating they would tell multiple friends. Three minors did not care who knew their results.

Reasons for sharing of the results included the recipient of the information having a good reason to know so that, for example, he or she could provide medical help or psychosocial support or information. Reasons to keep the results private included not wanting to be treated differently – minors at risk for heart disease in particular did not want to have their activities restricted.[168]

Here then is evidence that minors, some as young as ten years of age, can understand not only the medical, but also the longer-term and the psychosocial and privacy implications of genetic information.

The discussion of minors' understanding of genetic information shows that the process of educating minors about genetic testing, and exploring and personalising the longer term implications of testing for them is a useful method of conveying the information that they need to understand in order to give informed consent.

3.5 In what circumstances might it be necessary to assess a minor's competence to give informed consent?

Health professionals may need to assess the competence of a minor under the age of sixteen in many different circumstances. It might be necessary to assess a minor's competence to give informed consent when a minor under the age of sixteen is: seeking treatment on her own (or at least without her parents or legal guardians); seeking treatment with the support of her parents or legal guardians; or seeking or refusing treatment against the wishes of her parents or legal guardians.[169]

When a minor under the age of sixteen is seeking treatment on her own then the health professional will need to assess whether she is competent to give informed consent on her own behalf to the treatment that she is seeking: or whether the consent of her guardians is required.

When a minor under the age of sixteen is seeking a procedure or treatment with the support of her parents and/or family, health professionals should nonetheless encourage her to exercise her autonomy by participating in or making the decision, giving her the opportunity to be responsible for herself and her own body.[170]

Some of the professional position statements on genetic testing of minors, for example, the Australian NHMRC Information Paper, suggest that where both the young person and her parents agreed to testing, her parents' informed consent could be relied on as legally effective. In practice, the matter may be academic, as the health professional needs only one legally effective consent to treat; and yet it may be wise to get both the young person and the parents' consent in writing in the genetic testing context, so all parties take ownership of the decision. The competent minor's informed consent, however, would be sufficient to act upon.

However, it is also important to keep in mind that some minors may not want to make the decision: they may want the responsibility removed from them.[171] The HTA Code of Practice on Consent (2006) states that parents can give consent on behalf of their competent children if they choose not to make the decision.[172] The same is the case in New Zealand. While the health professional could rely on the competent minor's legally effective informed consent, he can also rely upon the parents' legally effective informed consent if the minor wishes to defer responsibility to her parents.

When a minor under the age of sixteen is seeking or refusing treatment against the wishes of her parents or legal guardians:

> *It is obvious where the child is vocal about their contrary opinion that the Gillick competence of the child should be examined. … Yet it will not always be clear under this scenario that Gillick should be invoked: a child may be silent on their wish and simply acquiesce to their parents' views because they do not realise that*

they potentially have a right to decide for themselves. Doctors should always seek to ascertain the patient's own views and potentially mention Gillick to ensure that the child is not conforming to his or her parents' wishes either unwillingly or ignorantly.[173]

3.6 What correlation is there between age and competence?

Despite the focus on 'maturity and understanding' rather than fixed ages in UNCROC, *Gillick*, the Code and the professional guidelines on genetic testing of minors (discussed later), competence is not entirely unrelated to age.[174]

Increasingly, research is revealing that minors have greater levels of understanding and sophistication at younger ages than previously thought. A study of postoperative pain in children under five years of age found that 75 per cent of the children could understand the concept of localising their pain, although only 41 per cent of staff thought that young children could do this.[175]

Research has also indicated that from around the age of eleven minors understand: that bad health can be aggravated by psychological factors; the idea of drug related side effects; and the prospect of delay before responding to a treatment or procedure.[176]

Weithorn undertook major empirical research into the competence of children and adolescents to make informed treatment decisions.[177] She interviewed ninety-six respondents, twenty-four (twelve males and twelve females) at each of four age levels: 8.5 to 9.5 years; fourteen years; eighteen years; and twenty-one years. The respondents were asked to consider which of the proposed treatment alternatives they might select if they were faced with the four hypothetical treatment dilemmas outlined (relating to diabetes, epilepsy, depression and enuresis). Their responses were judged according to evidence of choice;[178] reasonable outcome;[179] rational reasons;[180] and understanding (measured by rote recall to assess factual understanding and inference to assess appreciation).[181]

There were no statistically significant differences observed for sex.

In general, minors aged 14 were found to demonstrate a level of competency equivalent to that of adults … Younger minors aged 9, however, appeared less competent than adults according to the standards of competency requiring understanding and a rational reasonable process. Yet, according to the standards of evidence of choice and reasonable outcome, even these younger minors appeared competent. Children as young as 9 appear to be capable of comprehending the basics of what is required of them when they are asked to state a preference regarding a treatment dilemma. And, despite poorer understanding and failure to consider fully many of the critical elements of disclosed information, the 9-

year-olds tended to express clear and sensible treatment preferences similar to those of adults.[182]

In light of her findings Weithorn concluded that 'the ages of 18 or 21 as the "cutoffs" below which individuals are presumed to be incompetent to make determinations about their own welfare do not reflect the psychological capacities of most adolescents'.[183] Her findings indicate that the New Zealand statutory 'cutoff' of sixteen (section 36(1), COCA 2004) also does not reflect the psychological capacities of most minors.

3.7 What are the criteria for judging competence?

Much has been written on assessing the competence of minors, since the *Gillick* judgment. The following statement from Lord Scarman appears to best encapsulate what is meant by reference to the *Gillick* principle or *Gillick* competency (in New Zealand at least):[184]

a minor under the age of sixteen can give legally effective consent to medical treatment if he or she has 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed' (p 423).

The MOH produced helpful advice for health practitioners in a document entitled *Consent in Child and Youth Health* in 1999, which interpreted competence or capacity as: 'the ability or capability to make a rational, informed choice about accepting or refusing the treatment or service being offered, or authorising the collection and use of information'.[185]

Note that the guidance refers to competence as the '*ability or capacity* to make a rational, informed choice' and does not require that the choice made be in fact a rational choice.[186] In assessing whether a minor has such ability or capability, the MOH advised that, regardless of age, an individual must be able to understand:

- that they have a choice (freedom from coercion)
- why they are being offered the 'treatment'
- what is involved in what they are being offered
- what the probable benefits, risks, side effects, failure rates and alternatives are.[187]

The MOH further advised that competence 'must be considered on a case-by-case basis, taking into account not only the age of the child, but their functional maturity, the complexity of the information being given, the seriousness of their medical condition and the implications for the child of treatment and non-treatment'.[188]

The Medical Council of New Zealand advises:

> *Generally, a competent child is one who is able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment.*[189]

The NZPS Working Party Report recommended that:

> *An autonomous individual must be able to conceive and choose between possible futures for themselves, in the light of their own needs, desires and values. The qualities which are necessary for this include: the capacities to envisage and comprehend consequences (both short and long-term) of actions; understanding of relevant health-related ideas and issues; general capacities for decision-making, including the ability to weigh options and preferences; and a sense of one's own values, at least to the extent of having some sense of what would be a desirable life.*[190]

In the New Zealand case of *Re S* Barker, J implied that competence was related to appreciating the significance of the relevant treatment.[191] It is generally accepted that different degrees of competence are required in respect of different types of treatment, particularly with regard to the risks or possible consequences of treatment.[192] This issue is particularly salient in the context of genetic testing.

The significance of the nature of the procedure or treatment under discussion to assessing competence was recognised by the Law Lords in *Gillick:*

> *It seems to be me verging on the absurd to suggest that a girl or boy aged 15 could not effectively consent, for example, to have a medical examination of some trivial injury to his body or even to have a broken arm set … Provided the patient … is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express them validly and effectively to authorise the medical man to make the examination or give the treatment which he advises (per Lord Fraser at 409).*
>
> *I accept … that a doctor may lawfully carry out some forms of treatment with the consent of an infant patient and against the opposition of a parent … . The effect of the consent … depends upon the nature of the treatment and the age and understanding of the infant. For example, a doctor with the consent of an intelligent boy or girl of 15 could in my opinion safely remove tonsils or a troublesome appendix (per Lord Templeman at 432).*

For example, it has been argued that a nine-year-old could consent to being treated for a 'sore throat, an ingrown toenail or an ear infection' but it would be unlikely that he could competently consent to a tonsillectomy.[193] A health professional might respect the refusal of a ten or twelve-year-old child to consent to the removal of non-

dangerous mole (partly because of the difficulty inherent in removing a mole from an unwilling patient).[194]

The nature of the procedure or treatment is also relevant to the presumption of competence pursuant to the Code of Rights.

> *Thus while a child of 12 may be competent to consent to the setting of a broken limb, he or she may lack the necessary maturity and understanding to consent to heart surgery. The key under the Code is to consider each case on its own facts and not to lay down blanket rules.*[195]

Acknowledging that different levels of competence may be required for different procedures or treatments does not mean that different levels of competence may be required in respect of consent or refusal of consent for the *same* procedure. A minor does not have to be more competent to consent to a procedure or treatment, than to refuse consent to the same procedure or treatment, or vice versa. Part of the consent process requires an understanding of the consequences of not consenting to the proposed procedure or treatment: that is, understanding what the effect of a refusal would mean.

In summary, the general features involved in assessing competence relate to whether a minor understands: the *purpose* of a treatment or procedure; the *nature* of the treatment or procedure; and the *possible consequences* (including the short and long-term risks, benefits and harms) involved in having or not having the treatment or procedure. The minor must be able to make an informed choice between options, arguably, in light of what is (or will be) important to him or her.

3.8 Concerns with criteria for competence

> *There is a distinct judicial reluctance to define with any precision what it is that the competent adolescent must be able to understand in order to establish competence. The case law tells us that the courts set a high standard for adolescent decision-making. While 'a decision … made by [an adult] … does not have to be sensible, rational or well-considered',*[196] *an adolescent making the same decision must demonstrate considerable understanding as well as intellectual rigour and wisdom approaching that of Solomon.*[197]

A major concern with the criteria for assessing competence in minors, is that minors are often judged at a far higher standard than those set for adults. For example, both Weithorn[198] and Redding[199] consider 'reasonable outcome' or 'reasonable choice' integral criteria for measuring or demonstrating competence. The objective wisdom of a decision may affect whether or not a minor is deemed competent, whereas adults can make any unwise choices that they wish, and generally have those choices respected (so long as they are not unlawful and do not harm others).

> *There is also the temptation to equate a child's maturity and understanding with the views that a competent adult would hold in the given circumstances. That is, there is a danger that the assessment of competence will focus on ascertaining whether the child is making a wise decision, rather than on the child's actual capacity to understand (and intelligence).*[200]

The NZPS Working Party Report cautioned that:

> *Rejection of professionally recommended treatment by a child under 16 should not automatically be taken as evidence of lack of competence to decide their own health-care. The more serious the consequences of rejecting the treatment, the greater care must be taken in ascertaining the level of understanding and decision-making competence of the child.*[201]

However, it has been argued[202] (and also seen in the United Kingdom cases of *Re M*, *Re R*, and *Re W* and the *Laufau* case in New Zealand)[203] that a minor is more likely to be judged incompetent in situations in which his or her decision to consent to or to refuse to consent to a medical procedure or treatment is life-threatening.

In the United Kingdom case of *Re M*,[204] involving a fifteen-year-old girl who was refusing heart surgery without which she was certain to die, Johnson J said:

> *… M is an intelligent 15-year-old girl whose wishes should carry considerable weight. Nevertheless their view was that M felt overwhelmed by her circumstances and the decision she was being asked to make. A few weeks before M had been a healthy active girl, who loved netball and swimming, but now she is very ill and close to death. Events have overtaken her so swiftly that she has not been able to come to terms with her situation.*[205]

Kathryn McLean refers to the House of Lords judgment in *Airedale NHS Trust v Bland*[206] to argue that a competent individual's decision should be respected no matter how unreasonable or undesirable it might appear to others:

> *… the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so.*[207]

There is a concern that doctors assessing competence will be swayed by their professional biases and proclivity towards acting in a patient's best interest, and may judge minors competent when they agree to a doctor's proposed treatment, and incompetent when they disagree.[208] There is clearly much room for paternalism in assessing competence.

> *The rules which deal with capacity attempt to reconcile our paternalistic wish to protect the vulnerable with out overarching concern for the promotion of individual self-determination.*[209]

With reference to Lord Scarman's comment in particular that 'moral and family questions'[210] must be understood by a competent minor, Bainham has argued that: 'it is not obvious that the medical profession should be allowed to pass judgment on non-medical matters such as moral and family issues. …'.[211] We agree that a medical professional's subjective judgment of the morality of a minor's decision and of how her decision may affect her family members should not be a factor in assessing her competence. Note also however, that Lord Scarman's references to 'moral and family questions' were made explicitly in the specific context of a minor seeking contraceptive advice or treatment, and did not appear to relate to requirements for competence in other medical areas.

The perceived wisdom of a minor's decision should not be a part of the criteria for assessing her competence. It is more important that the minor has the ability to make rational decisions and work through the decision-making process rationally. Rational adults can disagree on all manner of issues, including whether or not to proceed with a certain medical procedure. For example, 5–20 per cent of adults at risk for the HD mutation elect to undergo predictive testing.[212] Many others elect not to undergo such testing. Neither group of individuals is necessarily irrational because they came to different decisions: the individuals presumably have different perceptions about the impact the genetic information will have on their lives.

Relying predominantly on the perceived wisdom of a decision in assessing competence could also be very misleading: Weithorn's research showed that nine-year-olds can reach the same medical decisions as twenty-one-year-olds,[213] but they do not necessarily arrive at those decisions via the same rational decision-making processes. It is the ability to comprehend and reason through the alternatives and the risks which is of tantamount importance. The perceived wisdom of the decision is overrated as a tool for assessing competence. In *Gillick* Lord Scarman and his colleagues focused on the ability to understand and the understanding of the minor making the decision, and not the outcome of the decision.

However, it may be appropriate, when engaged in the difficult task of assessing competence, to ask the minor for her reasons for making the decision that she has made. Otherwise, there is a danger that minors may reach decisions or conclusions based upon false premises. (Note that checking the consumer's understanding of the issues and reasons for making the decision could be equally beneficial for many adults). Asking for the minor's reasons may yield information about the *subjective* wisdom of the decision for the minor, and affirm that she has made an informed

choice between options in light of what is, or what she perceives will be, important to her.[214] In this manner, a health professional may be more assured that the minor understands the implications of the decision for her life and her future. This is the maximum extent to which the rationality of the minor's decision should be judged – the extent to which the decision is congruous with her stated goals and life plans. A choice that points clearly in the opposite direction of that which the minor has indicated that she values, or which will not assist her to attain her goals, may indicate a lacuna in her understanding or her reasoning processes.

The issue of protecting a minor from making a medical decision that will put her life at risk may not often arise in the context of genetic testing. The decision to undergo predictive or carrier testing will generally not be a life-threatening decision.[215] The decision to refuse predictive testing or carrier testing will similarly generally not be personally life-threatening, and in any case, it is a reversible decision.[216] Of course when any person is seeking or refusing treatment or a procedure that may have serious medical or psychosocial consequences, they must be carefully counselled as to their options and the risks and implications of each. Taking care to ensure that they completely understand the alternatives and risks will form part of the competence assessment for minors.

> *Competence is a relative not an absolute quality, and higher standards should not be expected from children than from adults …*[217]

4 DOES GENETIC TESTING RAISE DIFFERENT ISSUES IN TERMS OF COMPETENCE TO GIVE INFORMED CONSENT?

There is a great deal of evidence as well as academic and professional support for the idea that minors have sufficient intellectual or cognitive abilities to make medical decisions by their early teens.[218] However, whether they have the social and emotional maturity to make genetic testing decisions is more controversial.

A recent study put together by the Australian Institute of Family Studies[219] indicated that adolescents (between fifteen and eighteen years of age) had quite definite and rational ideas about what was or would be important to them both now and in the future. While many of the minors prioritised keeping fit, getting more education, having lots of friends, and sports and hobbies, they also believed that when they were thirty-five years of age they would attach more importance to issues such as a career, saving and investing, making a lot of money and relationships and children. The study indicates that whilst adolescents are (quite naturally) not concerned about adult issues in terms of their current existence, they have the foresight to recognise what issues will be important to them as they age. This suggests that minors faced with a decision about whether or not to have a pre-symptomatic genetic test may

have a greater understanding of the future implications than they are usually given credit for: this is particularly so given that these adolescents will generally come from families in which there is experience of a heritable genetic disorder and its impacts (see discussion on 'Experience of illness' later).

A study of young people in HD families found that 'there is no evidence to support the supposition that young people are too emotionally volatile to cope with information about HC'.[220]

4.1 Arguments in favour of a higher standard of competence for genetic testing decisions

Binedell et al. argue that 'the capacity for adolescent competence in decision making is apparent but whether or not adolescents exploit this capacity is constrained or facilitated by a number of factors'.[221] Adolescence is a period of transition in which minors are exploring and developing their identities, separately from their parents. 'It is a time of experimentation with new roles and fluctuation of values.'[222] Some consider that adolescents fail to weight the future appropriately and that their values are subject to change over time (more so than adults).[223] Additionally, peer pressure threatens autonomous decision-making and has been found to be strongest before the age of fifteen years.[224]

A change in values is certainly something that can occur amongst both minors and adults, and this is not necessarily an evil as people develop and grow in their understanding of various issues. It is possible that some adults may in the future wish that they had not undergone predictive genetic testing. This is not a reason to deny them access to testing: it is an impetus for careful consideration of the implications and likely consequences of genetic testing. Likewise for minors.

In terms of concerns about *peer* pressure, a minor may be more likely to feel pressured (whether overtly or otherwise) to *refuse* to undergo genetic testing, rather than to be tested and risk discovering that one is affected by a genetic mutation. Additionally, seeking or deferring to parental opinions when decision-making is not necessarily problematic in the genetic testing context. Indeed, it is natural for people to seek and be influenced by the views of others when deciding on a course of action: '…studies of adults might equally well show that they did what they thought their spouses or children would want'.[225]

Notwithstanding, few of the concerns have any impact on the legal test for competence. In particular, concerns relating to peer pressure or undue deference to parental wishes go more to the 'voluntariness' requirement for the giving of informed consent, rather than the competence criteria.

Richards argues that assessing the cognitive or intellectual competence of minors is insufficient in respect of genetic testing decisions, which have such potentially far-reaching implications. She claims that 'a far more comprehensive definition of maturity, linked to age and developmental age, is required for assessing young people at risk who request predictive testing'.[226] Richards suggests that 'maturity of judgement in decision-making' is the most important factor in assessing competence to give informed consent to predictive testing. She advocates Steinberg and Cauffman's model for assessing maturity of judgment, which identifies three aspects of psychosocial maturity: responsibility, which involves self-reliance, clarity of identity, and independence; temperance, the ability to limit impulsive behaviour and avoid extremes in decision-making; and perspective, which involves the ability to appreciate the complexity of situations and the long-terms consequences of decisions.[227]

However, Richards believes that it is important to strictly adhere to a minimum age of eighteen years for predictive genetic testing for untreatable late-onset disorders, for the following reasons: to provide a consistent structure for professionals dealing with requests for testing of minors of varying ages; to reduce dependence on arbitrary judgments of clinicians who may vary in their ability to make assessments of maturity; and because there was evidence that it was not developmentally possible for adolescents of fifteen and sixteen years of age to have attained sufficient maturity of judgment regardless of their life experience.[228]

Richards' first two points (in the preceding paragraph) are not substantive matters: they are procedural matters. It would certainly be easier for clinicians to have a simple age criteria for dealing with requests for testing from minors. However, such an approach does not reflect the law in New Zealand, gives no credence to the *Gillick* principle or UNCROC, and does not serve the health needs of minors. The third reason Richards offers for adhering to a strict age-based test is premised on the principle of universality. All minors do not develop uniformly and at the same time. In the context of genetic testing, it is precisely because of their unique life experiences, and current as well as future experiences, that some minors would seek genetic testing. It is not suggested that genetic testing be made available to all minors, but that it be provided to competent minors who request testing (after genetic counselling). Consistency is not a reason to support an inflexible approach to minors and medical decision-making.

Adhering to a strict age limit of eighteen years exchanges the potentially arbitrary judgments of clinicians who may vary in their ability to assess competence, to the equally, if not more, arbitrary judgment of a group of policymakers who have never met the minor who is requesting testing and know nothing of her individual circumstances.

Additionally, many adults may not be sufficiently competent to meet the criteria posited by the 'maturity of judgement in decision-making'. Indeed, Richards herself acknowledged that 'I have counselled eighteen-year-olds who have not achieved sufficient maturity' to make a decision about predictive testing for HD.[229]

Clarke has argued that another factor important to assess when considering requests for genetic testing from adolescents is 'why the request for testing has come now rather than in a few years, and why a test should be performed *now*, at this time rather than another'.[230] Similarly, Geller argues in response to a hypothetical case concerning a fifteen-year-old girl (Alison) requesting HD predictive testing:

> *The issue is not whether to test the Alisons of the world at all, it is whether to test them now. So the questions becomes: 'Are there compelling justifications, ethical and practical, to wait until the adolescent reaches the age of majority?' In answering this question, consideration must be given to the problem of scarce resources, both economic and human. The healthcare system is not currently set up for the extensive counselling and assessment that is being recommended to assess the competence of adolescents who might request such testing.*[231]

Whether a test can safely be performed later, when the minor reaches the age of majority, is not a factor to be considered in assessing whether a minor is competent to make the decision. The fact that a test could be performed later does not make the minor any less competent to choose to undergo testing now. However, the option of deferring testing can be discussed with the minor, particularly so that the minor is entirely clear that there will be minimal or no clinical harm from waiting. Resourcing issues are beyond the scope of this section of the report.

Related, refusing to test minors on the basis that they do not intend to make reproductive decisions in the near future, would be inconsistent with the grounds upon which adults are tested: many adults are tested for HD who have completed their families, and are seeking the information for other reasons.[232]

There may be compelling ethical and practical justifications not to defer testing until the age of majority: many minors are living with knowledge that they at risk, some live as if they definitely have inherited a mutation, some engage in risk-taking behaviours, and others feel like they are 'holding their breath' until they can be tested. Deferring testing on the basis of age has the potential to harm and demean competent minors. The need to respect the autonomy and decision-making rights of competent persons is also a compelling justification for not deferring testing on the basis of age alone. It is paternalistic and discriminatory to select a group of competent, autonomous individuals and deny them access to genetic testing.

Duncan refers to the concern of the United Kingdom CGS Working Party that because a decision to test a minor was irreversible, professionals might be considered liable in the future if an adult claims that she never should have been tested as a child: 'there are good legal reasons for professionals to make decisions in this area primarily on the basis of the long term best interests of the child; failure to do so could lead to professionals later being sued'.[233] Regardless of the likelihood (or not) of any such claim succeeding, advocating that minors who appear competent in every way be refused genetic testing because of a fear of professional liability, swings the pendulum too far in favour of the practice of defensive medicine. While minors may be encouraged to take extra time to make a decision about genetic testing, this should only be encouragement, not coercion, and not a method of avoiding testing a minor for self-interested professional reasons.

Wertz et al. have argued that there are four requirements to competence to consent to genetic testing:

1. *Voluntariness;*
2. *'Reasonable outcome' of a choice in terms of the individual's and family's social and cultural situation and lifestyle;*
3. *Sound reasons for the choice; and*
4. *Understanding of risks, benefits, and alternatives, including knowledge of both facts and implications.*[234]

They argue that there may be difficulty in assessing whether a minor's request for or consent to testing is voluntary. However, the voluntariness of consent goes to whether the informed consent is valid, not to whether the person is competent to make the decision. Competent people can be pressured into making certain decisions: such does not make them incompetent, although it may make the consent given ineffective.

Caulfield suggests that these criteria for competence 'could be considered an extreme position'. He argues that such criteria have no basis in law (in Canada at least), and that relying on them could result in a very paternalistic approach to assessing competence. For example, what is a 'reasonable outcome' and what are 'sound reasons for the choice?' Caulfield argues that the legal test for competence is not as onerous as ethical tests appear to be.[235]

The debate about whether minors can be competent to give informed consent to genetic testing often gets mired in the appropriate criteria for assessing competence, and whether it is possible for minors to meet the stipulated criteria. Much of the debate in the literature pertaining specifically to minors and genetic testing decisions focuses on what might be regarded as ethical criteria for competence. However, the question of whether minors are competent to give informed consent to genetic

testing is a question of facts, which are to be measured against legal criteria, not ethical criteria.

Competence is important as a necessary competent of informed consent, which is only *legally* effective when it is voluntary, informed, and given by a competent person.[236] Health professionals can generally not lawfully administer medical procedures or treatment to a person without the informed consent of the competent person authorised to give consent (whether that be the person themselves or their legal representative or guardian if they are not considered competent).[237] The criteria for judging competence are legal criteria.

Criteria for assessing competence are not laid out in any legislation in New Zealand. The major common law authority on the competence of minors to consent to make their own medical decisions is *Gillick*. The following statement from Lord Scarman appears to best encapsulate what is meant by reference to *Gillick* competency (in New Zealand at least):[238]

> *a minor under the age of sixteen can give legally effective consent to medical treatment if he or she has 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed' (p 423).*

The criteria are general and very broad and have been applied to mean that minors under the age of sixteen must understand the purpose, the nature, and the consequences and implications of the decision in question in order to be competent to give legally effective informed consent (or refusal of consent).

Arguably, health professionals may also consider whether the minor's choice accords with her stated goals or aspirations post-testing. A choice that points clearly in the opposite direction of that which the minor has indicated that she values, or which will not assist her to attain her goals, may indicate a hole in her understanding or her reasoning processes. Thus a 'set of values' may be included within the more general legal requirements of competence, so long as the criterion is restricted to having a conception of the good life for oneself, and assessment of whether the choice evinced is commensurate with that conception – if it is then it would appear that the minor understands the implications of testing. The question is not whether the minor's conception of the good life, or goals or aspirations, is appropriate or not.

> *An autonomous individual has every right to make what most would consider a 'bad' decision.*[239]

As Binedell et al. argue: 'the focus of the assessment should be on the decision making process rather than on the final decision made, there being no "right" decision in this case'.[240]

Competent minors should not have their access to genetic testing restricted on a different basis from any restrictions that might apply to adults; that is, all persons who are competent, on the formulation articulated in the preceding paragraphs, should be treated equally in respect of requests for genetic testing.[241] Minors should not be required to jump through hoops to meet criteria for competence that many adults may not be able to meet, and that the minors themselves may never be able to meet, even as adults.

4.2 Experience of illness

It is a contentious issue whether minors at risk for heritable genetic disorders are more competent to give informed consent to genetic testing, or less so, because of their lived experiences.

> *… I think if your parent has it and you've seen the consequences of it, I think you have every single right, no matter what age, to get tested.*[242]

We have seen that minors are able to understand information about heritable genetic risks: 'We simply cannot assume that children are not capable of understanding genetic knowledge or that they are better off not being told when they have experienced the consequences of genetic conditions within their families'.[243]

Alderson argues

> *If they do not have such direct personal experience then however mature and intelligent they are, their understanding and wisdom are likely to be much more limited. Children with experience of serious illness or disability and treatment, even if they are well below average at school, can have high level of competence concerning decisions about their health care.*[244]

Richards suggests that some minors will be pseudo mature, their behaviour mimicking that of adults (given the roles that they may have had to adopt) 'without being accompanied by the perceptions, beliefs or understanding of a psychologically mature adult'.[245] Similarly, Wertz et al. caution that 'well-informed, articulate children or adolescents are not necessarily coping well with the prospect of illness'.[246] However, many adults do not cope well with the prospect of illness: minors should be judged upon the same standards. Rather than a minor's request for testing simply being dismissed because of a perceived lack of coping skills, coping mechanisms need to be carefully considered in genetic counselling. The discussion in the second section of this report on 'Benefits and harms' provides some evidence to suggest that some minors cope reasonably well with genetic test results.

Research into the psychological and genetic counselling implications for daughters (between eleven and nineteen years) of mothers with breast cancer[247] indicated

that there were no significant differences between the daughters of mothers with breast cancer and those from families with no major health issues, on measures of emotional, behavioural, social and familial functioning (self-reported by daughters and mothers). All daughters were well within the normal range of functioning.[248]

Daughters of mothers with breast cancer were naturally significantly more concerned with their perceived risk of inheriting a BRCA mutation and developing breast cancer. A large minority (40 per cent) said that their worries about breast cancer somewhat or 'to a fair bit' affected the way they felt from day to day. However, 60 per cent indicated that worries about breast cancer did not at all affect the way they felt from day to day.[249]

Minors seeking testing for a heritable genetic mutation may generally be more contextually competent than minors consenting to other medical procedures: most of them will have some experience of the relevant genetic condition, given their family history which places them at risk. Even amongst those who do not have personal experience, they may still be as competent to make a decision about testing as an adult who similarly has no personal experience of the relevant condition.

How a minor has reacted and adapted to the information and experience of the genetic mutation in the family may be a useful predictor of how the minor might react and adjust to the test results.[250]

> *Parents may not be emotionally available to help their children with the impact of testing procedures or results because of their own illness or guilt over issues of inheritance.*[251]

A minor might have extensive experience of a disorder within her family but if all of that experience is secretive, negative, and terrifying, then it may not enhance her competence to make a decision about whether to be tested. Whereas, if she has been raised in an open and honest, supportive and nurturing environment then, as result, she might very well be more competent to make a decision about testing. The need for a careful individual assessment of each minor who requests genetic testing is clear.

4.3 Arguments relying upon arguably outdated views of minors

> *Psychological testing tends to be biased by outdated developmental theories which under-estimate children's abilities.*[252]

In the discourse surrounding genetic testing of minors, commentators frequently adhere to arbitrary ages when referring to theories of child development or categorising minors' cognitive abilities or developmental steps.

Binedell et al. argue that competence needs to be defined and indeed only has meaning with reference to the social, cultural, and institutional context. On this

analysis the degree of a person's competence is affected by external factors, such as parental attitudes and expectations, and the state of medicine, the law, and media. All of these external factors are instrumental in determining notions of minors' abilities, rights and responsibilities. Prevailing conceptions of children and adolescents have an impact on the way that competence is developed and assessed.[253]

> *For example, children's competence would be enhanced where parents see them as responsible and trustworthy, informing them and involving them in decision making. Conversely, competence would be inhibited where parents adopt a controlling or protective stance toward their children, withholding information from them. Features of the clinical setting in which testing takes place could hinder adolescents' capacity to make competent decisions by, for example, a lack of space to sit and talk quietly.*[254]

The world and the minors within it are experiencing a period of rapid change. Globalisation and the internet have resulted in an unprecedented dissemination of every conceivable kind of information throughout the world. Minors who know that they are at risk for a heritable genetic disorder may know about advances in knowledge about their condition. They may very well have done their own research into the disorder on the Internet. 'These discoveries are reported everywhere, not only in medical journals, but in the lay press as well.'[255]

Studies have shown that a large number of patients and parents of paediatric patients use the internet to find out health information. Younger people are more likely to be familiar with the use of computers and the internet: 'other studies reporting a high rate of internet use for medical information site [sic] younger age as a factor significantly associated with such use of the internet'.[256]

Regardless, it is important that health professionals assess the minor's competence as an individual and not on a generic concept of what minors are presumed to understand or not understand.

> *… the courts have recognised that, where possible, irreversible decisions should be left for children to make when they reach maturity.*[257]

If it is thought that different levels of competence may be required for consenting than for refusing consent to treatment (which we have indicated above that we do not accept) then it is arguable that *refusing* consent to genetic testing requires a *lower* standard of competence than consenting. Consenting to genetic testing is irreversible and may have more serious consequences than refusing to give consent to testing. In contrast to some other medical procedures or treatments, it might be argued that a lower standard of competence is required to refuse consent to genetic testing, than the competence required to consent. Consenting to genetic testing can have greater implications that need to be explored and understood.

Even when testing is not clinically indicated, there can be serious implications to rejecting genetic testing too, not least of which relate to reproductive decisions. For example a minor at 50 per cent risk of carrying an untreatable autosomal dominant genetic mutation has a 25 per cent risk of passing the mutation onto any child she bears. However, a refusal to be tested can be reversed, whereas consent to testing cannot, and thus the implications are arguably more serious, and some may consider that the degree of competence required is higher. We reiterate that we consider the same standard of competence is required to give informed consent or refusal of consent to *any* medical decision.

4.4 Professional position statements and assessing competence

The Human Genetics Society of Australasia policy on *Predictive Testing in Children and Adolescents* (2005)[258] offers the following guidance to practitioners in assessing the competency of a minor to consent to a predictive genetic test:

- There must be full discussion with the child about the testing, risks and implications.
- Discussion between parents and child is to be encouraged.
- The child must demonstrate an understating of the nature of the test, risks, benefits and implications.
- Psychological testing may be important to assess the psychological state of the child.
- A second professional opinion may be appropriate.

The HGSA policy also recommends that consultation with medical geneticists, genetic counsellors and psychologists could be considered to assess the child's level of competence. This guidance to professionals in terms of what kinds of things are relevant when assessing competency is very similar to the general assessment of competence seen above. Thus, the policy does not suggest a novel approach, and nor does it appear to infer that a higher level of competence is required than that in a more general clinical setting.

The Canadian Paediatric Society *Guidelines for genetic testing of healthy children* state that children as young as four can understand ideas of inheritance. Seven year olds have generally begun to develop 'concrete concepts of health-related procedures … correlating with the acceptance of "assent" ...'[259] The *Guidelines* contend that full understanding of the nature and consequences of agreeing to or refusing medical management does not occur until early adolescence, or even later. The capacity to understand abstract ideas of social risk, including loss of privacy, social stigmatisation and potential insurance or employment discrimination may require even greater

insight. The Guidelines also note that many adults have difficulty understanding probability and risk in terms of genetic test results.[260]

The American Society of Human Genetics and American College of Medical Genetics Report 'Points to Consider, Ethical, Legal, and Psychosocial Implications of Genetic testing in Children and Adolescents' (1995) states that minors can begin to participate in decisions by the age of seven because they have sufficient cognitive and language skills to understand some information. Therefore, in the United States seven-year-olds are entitled to give 'assent' to participation in research.[261]

> *Decisions about competence should not depend arbitrarily on the child's age but should be based on an evaluation of the child's cognitive and moral development. The provider should also attempt to establish that the child's decision is voluntary.*[262]

The report explains that competence in decision-making depends on the possession of three broad capacities: understanding and communication; reasoning and deliberation; and development and sustenance of a set of moral values.[263]

The report acknowledges that minors might have a genuine interest in career or child bearing choice, despite their still being vulnerable to coercion, stigmatisation and altered self-image. The report charges that by the age of twelve or fourteen some minors will have sufficient decision-making capacity to evaluate specific risks and benefits of tests and treatments.[264] According to this report, genetic testing decisions do not seem to require a higher degree of competence than other medical decisions. The assessment criteria outlined are similar to those discussed in the more general section on competence.

Likewise, one cannot infer from the United Kingdom CGS Working Party Report that a higher standard of competence is required to consent to genetic testing. The report simply refers to *Gillick* and the fact that some minors under the statutory age of consent may be competent to give informed consent to medical procedures.[265]

4.5 How is competence to be assessed in practice?

4.5.1 Who should assess a minor's competence?

The MOH cautions that 'while the views of the parent or carer as to the child's competence may be taken into account, it is the practitioner's responsibility to form an independent judgement on the matter'.[266] This will of course be necessary where the minor seeks treatment alone, or against the wishes of her parents. But it will also be important when the child appears to be in agreement with her parents.

While there is a presumption of competence within the Code:

> *In practice, no health practitioner actually presumes a 5 year old competent*

till [sic] proven otherwise. Reality and practicality work from a presumption of incompetence for children. … doctors should not be bound to undertake a specific and conscious inquiry in every treatment situation for an under 16 year old. … doctors must be allowed a discretion to determine when it is appropriate to undertake an express inquiry into the competence of a child patient and when 'reasonable grounds' exist so that no express inquiry is necessary.[267]

It has been noted that doctors generally receive little training in assessing the cognitive development of children

and may be quite ignorant of personal circumstances (which include aspects relating to the child's familial relationships) affecting a child's maturity and understanding of the procedure involved. These concerns are more significant if the doctor's consultation time is limited, as is often the case.[268]

Kathryn McLean has also criticised the appropriateness of health professionals assessing competence, saying that 'they will be swayed by their professional biases', and that they are 'particularly influenced by their view of a patient's best interests'.[269]

Furthermore, there is the concern that within the medical community there will be inconsistency in the application of Gillick due to personal views and beliefs. This may be particularly noticeable in areas that raise social, religious or moral issues …[270]

She accepts, however, that health professionals must be responsible for assessing the competence of minors, citing as relevant factors: they are experienced at assessing competence; there may be no other group more appropriate to make such assessments; and health professionals are the ones who will be administering or refusing treatment and 'therefore it must be the doctor who is satisfied that he or she is justified in doing so'.[271]

Family doctors may be at an advantage in assessing the competence of a minor, if they have prior knowledge of the minor's abilities, maturity and family background.[272] Clinical geneticists and genetic counsellors may also build up relationships with families 'as they have their children and as the extended family come in to discuss how a condition might affect them'.[273]

Genetic counselling is currently standard practice before predictive, susceptibility and even carrier testing for certain serious late-onset disorders will be undertaken (e.g. HD, adrenoleucodystrophy and tests for a BRCA mutation or other hereditary cancer testing). The HGSA Policy on *Presymptomatic and Predictive Testing for Genetic Disorders* recommends:

It should be ascertained at the outset why a person has come forward for testing and his (or her) expectations of the test. … Those providing testing need to ensure

that all the implications of testing have been considered, and counselling should be available for as many sessions as necessary.[274]

Genetic counsellors are trained not only in genetics, but also in interviewing and counselling.[275] Genetic counselling, undertaken in the manner recommended by the HGSA, could provide a very suitable forum within which a minor's competence to give informed consent to genetic testing may be assessed. The HGSA further recommends that:

A test should only be performed on an individual who has made an informed voluntary decision to have the test. There should be no pressure from third parties, including family, friends, health professionals … Prior to written consent being sought, written as well as oral information should be given in clear and concise English. … General information about the disorder being tested should include the clinical features, age of onset, variability of clinical features, genetic basis, pattern of inheritance, and availability of prevention, surveillance and treatment strategies. Details of the test and the testing process should be explained. Reproductive options should be discussed, if relevant. Information should be provided about lay organisations and genetic registers that exist to inform and support families with a genetic disorder. The clinician should ensure that the pre-test information is understood. The individual to be tested should have the opportunity to discuss testing with family and friends. A consent form should be read, understood, and signed by the person being tested. …[276]

The genetic counsellor must go through a careful information giving and checking process to ensure that *everyone* seeking genetic testing understands the implications. She must ensure the voluntariness of any consent given. Voluntariness is a vital component of informed consent, and particularly so: in the genetics context where the medical decision will have information implications for other family members; and for minors who may be particularly susceptible to family pressure for testing. Reproductive issues also need to be canvassed for minors who may intend to have children themselves in the future. Ultimately, a primary task of the genetic counsellor is to explain fully the testing process and its implications for the particular disorder in question; to confirm understanding of the information imparted; and to support the decision-maker. This role seems well suited to incorporating assessing requests for genetic testing from minors.

Another recommendation contained in the HGSA policy may further reassure the genetic counsellor, and perhaps even the minor and/or family, that the minor is not rushing into a rash decision:

People should not rush into a test. It is usually advisable to allow a period of some

weeks between providing information and initial counselling and subsequently obtaining consent for a test and taking the sample.

Where, during or after genetic counselling, doubt remains as to a minor's competence to consent to genetic testing, and predictive testing in particular, it may be advisable to involve a child psychologist or psychiatrist.[277] Psychological and psychiatric assessment of persons undergoing HD predictive testing has not been for the purposes of gate keeping (except to the extent that people with serious psychiatric illnesses or suicidal tendencies may be excluded); it has been for the purposes of identifying factors predictive of coping responses and enhancing the planning of appropriate support after the decision is made.[278] Psychological or psychiatric assessment of minors presenting for *predictive* genetic testing could therefore serve the dual function of providing somewhat of a gate-keeping role in terms of assessing competence to make the decision, but simultaneously could identify predictors of post-decision reactions and needs.

4.5.2 How is competency to be assessed?

Health professionals may assess the competence of the minor by explaining the purpose, nature and potential consequences of the treatment in a manner and in language that the minor can understand. The health professional may question the minor to clarify the extent of his or her understanding and competence in respect of the decision to be made.

> *From their first interaction with a patient, doctors will have begun to assess a patient's competence and abilities; the process of assessment will be an on-going one. The appropriate time to conclude an assessment of Gillick competence is once a child has evinced a choice in regard to a particular treatment decision. Until this point it is unclear whether the assessment concerns the child giving or refusing consent. Furthermore, to judge competence a doctor may require a child to articulate the reasons for his or her decision.*[279]

Larcher has offered the following model of practical advice for assessing competence:

> ***General principles***
>
> - *Treat adolescents as you would competent adults unless you have reason to doubt their competence.*
> - *Guarantee confidentiality unless there are specific reasons to break it.*
> - *Make every effort to involve their family (Fraser guidelines).*
> - *Use open ended questions that prompt discussion.*
> - *Use colloquialisms but not jargon.*

- *Be non-judgmental – make no presumptions about the young person's views or abilities.*
- *Aim to increase their competence.*
- *Encourage young people to express their own views.*
- *Challenge expectations that adults hold decision making power.*

Specific issues

- *Ascertain what the young person knows about their illness or problem and its treatment.*
- *Ascertain their personal experience of illness.*
- *Ascertain their previous experience of decision making for their condition or issue – for example, whether they have been previously involved with parents' decision making.*[280]

4.5.3 Assessing competency to give informed consent to genetic testing in particular

Wertz, Fanos and Reilly suggest that new measures are needed to enable professionals to evaluate a minor's competence, perhaps through open-ended questions about the future or responses to vignettes describing future life problems, and careful interviewing.[281]

New measures for assessing competence in the context of genetic testing may be appropriate or helpful, but the same standard of competence is required. Minors should not be expected to know more than they are expected to know of other procedures, and they should not be expected to have greater understanding than adults.

Binedell offers some guidance for the kind of information professionals should look for when assessing competence to give informed consent to genetic testing. Her guidance is in respect of HD specifically, but the principles are more universal. Her model for assessment has been widely endorsed.[282] The information to be sought has some commonality with Larcher's recommendations in respect of assessing competence to consent to medical procedures generally:

The following information may be useful in the assessment process:

(i) The length of time that the adolescent has lived with knowledge of HD in the family and being at risk. An individual will know the most about those risks that he/she has been dealing with the longest (Fischhoff, 1992), therefore the length of time lived with an at-risk status will be a significant factor in the adolescent's ability to evaluate the costs and benefits of living at risk versus receiving a test result.

(ii) Adaptation to knowledge of HD in the family and being at risk. This has

been identified as a good predictor of how an individual will cope with a test result (Wexler, 1979).

(iii) Absence of any controlling influences in the decision to ensure that the adolescent is the primary decision maker. Does the adolescent assume or avoid control in decision making? What is the adolescent's primary reference group with regard to decision making in this context?

(iv) Adequate information concerning the salient aspects of the test procedure and its implications. Is this knowledge accurate and is it being applied in the decision?

(v) Appreciation of the broader social and emotional implications of the result for the individual and the family, both in terms of short-term and long-term interests and concerns. What is the nature and number of the costs and benefits considered in reaching a decision?

(vi) The stability and consistency of the decision and the reasons for the decision over time.

(vii) Assessment of the role of the family context in the request and the function of the request in the family at the time. Does the request stem from a need to confirm beliefs about preselection (Kessler, 1988) or to resolve an anomalous situation where there is clarity about the genetic status of some but not all family members? An unresolved family conflict may underlie a request for testing and signal that intervention is needed at another level.

(viii) Past opportunities for the development of competence in decision-making. What is the pattern of sharing information and making decisions in the family? How and by whom are decisions usually made?[283]

Binedell further suggests that in the absence of standardised tools for assessing competence in the clinical genetics context, minors should be referred to professionals with expertise in the area such as clinical psychologists and psychiatrists (and also suggests that this occurs within a research protocol). However, we think that if genetic counselling is undertaken with due care and deference to the guidance from the HGSA Policy on *Presymptomatic and Predictive Testing for Genetic Disorders*, genetic counsellors may have the information and tools required to assess a minor's competence in the clinical genetic context. They have training and experience in interviewing and counselling with respect to genetic disorders, and could use Larcher and Binedell's guidance in respect of assessing the understanding of minors, in particular. Additionally, the discussion of minors' understanding of genetic information shows that the process of educating minors about genetic testing, and exploring and personalising the longer term implications of testing for them is a

useful method of conveying the information that they need to understand in order to give informed consent.

Binedell notes that as is the case with at risk adults, many minors who seek testing will decide against it during the counselling process. These people may also require some psychological support to live with the continued uncertainty.[284]

4.6 Comments

Genetic testing raises the same issues in terms of competence to give informed consent, as other medical procedures: consent must be given voluntarily, on an informed basis, by a competent person.

Genetic information may be more complex, and may contain more uncertainties or probabilities than other medical information. This provides a challenge for health professionals to fulfil their obligations under the Code and give consumers, including competent minors, the requisite information to enable them to give legally effective informed consent. The information must be given in such a way that minors can understand it. There is evidence that adequately educated and informed minors can understand the necessary genetic information to give informed consent to testing.

Some have argued that consenting to genetic testing requires a higher degree of competence than consent to other kinds of medical procedures, because of the ethical, psychological and social issues. However, the *legal* criteria for assessing competence remain the same: the person must understand the purpose of the procedure, the nature of the procedure and the consequences and implications. It may be necessary to give minors more information about the longer-term implications of testing as they may not previously have had cause to consider such issues. They should not, however, be held to higher standards for decision-making than adults are held to. The wisdom or rationality of the actual decision is irrelevant to a competence assessment except to the extent that one may consider whether the decision accords with the minor's self-professed goals and desired outcomes of the decision. It is not the role of the health professional to second-guess or judge the minor's goals. However, he or she must ensure that the minor has made the decision based on all of the relevant information – an incongruity between the choice evinced and the stated goals or desired outcomes of the choice may indicate a lack of understanding or insufficient information upon which to make the decision.

Many of the professional position statements from various countries offer guidance for assessing competence in the context of genetic testing that is similar to the more general approach to assessing competence: they do not appear to imply that there are different criteria for assessing competence in the context of genetic testing.

Genetic counselling is usually required before predictive or carrier testing for serious disorders will be undertaken, providing an ideal forum within which a minor's competence can be assessed. Larcher's model, coupled with Binedell's useful questions for professionals to consider when exploring whether minors understand the purpose, nature and consequences and implications of genetic testing, provides an appropriate extra tool for assessing the competence of minors to give legally effective informed consent in the clinical genetics setting

5 CONCLUSION

As outlined at the beginning of this section, self-referral for genetic testing by minors does occur, albeit rarely.[285] The two major objections to permitting minors to consent to genetic testing are that: genetic testing is too harmful for minors; and genetic testing, and its implications, are so complex that minors could not be competent to give valid informed consent to testing.

There is no explicit regulation or policy relating to genetic testing of minors in New Zealand. In our view competent minors can consent and also refuse consent to all kinds of genetic testing, pursuant to section 36(1) of the Care of Children Act 2004 (if they are of or over the age of sixteen). *Gillick* as applied in New Zealand, the Code of Health and Disability Services Consumers' Rights 1996, the United Nations Convention on the Rights of the Child and the New Zealand Bill of Rights Act 1990 also support this view.

Once a minor is deemed competent (statutorily, or in light of her maturity and understanding) then harms and benefits become largely irrelevant (except to the extent that any health professional can refuse to provide services that have no medical benefit), and competent minors' requests for testing should be treated in the same manner as requests by adults. However, if the reference in section 36(1) of the COCA 2004 to benefit is taken to mean that sixteen and seventeen-year-old minors can only consent to procedures that are intended to benefit them, they can still consent to genetic testing, whether or not treatment is available for the disorder for which they are seeking treatment, because there are benefits in knowing one's future genetic health status.

At the time of writing there appears to be more convincing evidence for the *benefits* that arise from genetic testing (some of which are knowable *a priori*), than the purported harms, in respect of competent minors who request genetic testing.

There is a distinct paucity of evidence of actual harm arising from genetic testing of minors, and harms specifically related to competent minors are even more speculative. Additionally, some of the projected harms can already be seen in minors living 'at risk' for a heritable genetic mutation: harm can arise from not acceding to a competent minor's request for genetic testing.

Thorough genetic counselling, and an *individual* assessment of the minor's competence to consent is vital before a minor makes a decision about whether to undergo predictive genetic testing or carrier testing. The benefits and harms of testing frequently appear to be dependent on the individual's life story and relationships prior to testing, and plans and level of support available after testing.

Some have argued that consenting to genetic testing requires a higher degree of competence than consent to other kinds of medical procedures, because of the ethical, psychological and social issues. However, genetic testing raises the same issues in terms of legal competence to give informed consent, as other medical procedures: consent must be given voluntarily, on an informed basis, by a competent person.

Genetic information may be more complex, and contain more uncertainties or probabilities than other medical information. However, this provides a challenge for health professionals to fulfil their obligations under the Code and give competent minors the requisite information in such a way that they can understand it and give legally effective informed consent. There is evidence that adequately educated and informed minors can understand the necessary genetic information to give informed consent to genetic testing.

The legal criteria for assessing competence remain the same in the context of genetic testing: the person must understand the purpose of the procedure, the nature of the procedure and the consequences and implications. Notably, professional position statements on genetic testing of minors do not appear to imply that there are different criteria for assessing competence for purposes of genetic testing.

Larcher's model for assessing competence, coupled with Binedell's questions to consider when exploring whether minors understand the purpose, nature and consequences and implications of genetic testing, may provide appropriate tools with which genetic counsellors (and others) can assess the competence of minors to give legally effective informed consent in the clinical genetics setting.

> *In conclusion, the issue is complex and troubling. It illustrates the importance of considering each patient as an individual, with particular needs, values and objectives: that a decision to administer or nor to administer the procedure must be determined on a case by case basis, and not as result of predetermined values, objectives, and policy.*[286]

The medical decision-making framework in New Zealand is largely appropriate in its application to genetic testing and competent minors, and despite the 'passionate debate', competent minors' requests for genetic testing do not require a vastly different regulatory response.

ENDNOTES

1 Julia Binedell 'Adolescent requests for predictive genetic testing,' pp123-132 in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998, cites findings from a European Community Collaborative HD Study (1993) that self -referral by adolescents does occur, although rarely. See Table 1, p 125. Additionally Duncan et al surveyed 301 respondents from the USA, Canada, the UK, Australia and New Zealand who were professionally involved in predictive genetic testing as to: their involvement and attitudes in relation to predictive genetic testing of pre-symptomatic children for untreatable conditions; and their views on the existing guidelines on the predictive testing of children. Of the twenty-seven reported cases of testing of mature young people, in four cases (15 per cent) the young person's parents requested the testing, and in ten cases (37 per cent) the young person him or herself requested testing. In the remaining thirteen cases (48 per cent) the request for testing came from both the young person and their parents. The survey undertaken by Duncan et al provides the most recent evidence of professional practice in relation to genetic testing of minors. It is also one of the most geographically broad surveys. (Rony Duncan, Julian Savulescu, Lynn Gillam, Robert Williamson, and Martin Delatycki (2005) 'An international survey of predictive genetic testing in children for adult onset conditions' *Genetics IN Medicine* Vol. 7, No. 6, 390-396).

2 Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005, p 66 (accessed from http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf, on 17 September 2006).

3 Allyn McConkie-Rosell and Gail A. Spiridigliozzi (2004) 'Family Matters: A Conceptual Framework for Genetic Testing in Children' *Journal of Genetic Counseling*, Vol. 13, No. 1, February 2004, p 11.

4 See Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 565-566.

5 According to s 8 of the Care of Children Act 2004, a child is a person under the age of eighteen years.

6 Bill Atkin has argued that s 36 is limited by the arbitrary age of sixteen (see discussion below on the effects of *Gillick* and s 36 of the COCA 2004 in New Zealand), particularly as the new Act lowered the age at which guardianship ended to eighteen years: thus the scope of s 36(1), which covers sixteen and seventeen-year-olds only, is fairly narrow. He also argues against the arbitrary age rules reproduced elsewhere in the Act. For example, s 46: why should a mature fifteen-year-old (or any child for that matter) not also be able to challenge a guardian's decision (as any child can apply for a protection order, through a representative pursuant to the Domestic Violence Act 1995)? Atkin, Bill, 'The Care of Children Bill – Alright but only as far as it goes', accessed from www.conferenz.co.nz/2004/library/a/atkin_bill.htm, 26 May 2006.

7 Mark Henaghan *Care of Children* LexisNexis NZ, Wellington, 2005, p 19.

8 Oxford English Dictionary (online) accessed 9 January 2007 from http://dictionary.oed.com/

9 See the United Kingdom cases of *Re R (a minor)* [1991] 4 All ER 177, *Re W (A Minor)* [1992] 3 WLR 758, and *Re M (child: refusal of medical treatment)* [1999] 2 FCR 577.

10 The common law rules of competence are discussed further at pp 8-16.

11 Predictive genetic testing for conditions that have no beneficial medical interventions is often considered to be non-therapeutic in nature because there are no medical therapies available. Carrier testing may also be considered non-therapeutic given that the test result generally has no physically therapeutic benefits for the minor tested. It might be argued that the benefit proviso is aimed at limiting the right of sixteen and seventeen-year-olds to consent to procedures that are for another person's benefit, as opposed to for their own. This may be the motivation, rather than restricting the right to consent to treatment or procedures to interventions that have clinical benefit only. Most of the discourse on consent to non-therapeutic treatment or procedures on children relates to organ donation and non-therapeutic research. Both of these kinds of procedures

are carried out primarily for the benefit of another person(s), and not the prospective donor or research participant. Arguably, it is these types of scenarios that the benefit proviso envisages. For example, see Cordelia Thomas (2000) 'The intolerable dilemma: Refusal of consent for the medical treatment of children' 3 *BFLJ* 173: 'This presumably prevents consent to organ donation and medical experimentation, as these do not medically benefit the young person.' Much of the literature on whether or not organ donation or non-therapeutic research is for a minor's benefit or in a minor's best interests is irrelevant to discussion on whether minors can consent to procedures that are not clinically indicated but may be beneficial to them nonetheless. Different issues apply. The literature on organ donation generally focuses on children who are too young to give their own legally valid consent or refusal and issues such as substituted judgment, forced altruism, and best interests. There are also known clinical risks attendant upon organ donation, particularly donation of non-regenerative organs or tissues e.g. anaesthetic risks generally, and the risk that one may need a spare kidney, for example, in the future. It is often argued that claiming that organ donation is in a donor minor's best interests is a disingenuous way of arriving at the desired decision that organ donation is ethically permissible. Concerns naturally revolve around the potential for exploitation and the imposition of clinical risks with no or very little benefit to the prospective minor donor (as do concerns with the involvement of minors in non-therapeutic research). The issues relating to competent minors who are seeking a treatment or procedure which may have no clinical or physical benefit are very different. The need to protect minors from exploitation and clinical risks is not generally in issue when a competent minor is seeking a genetic test, for example, for her own purposes eg to alleviate the anxiety of uncertainty, and/or to assist in career and life planning. The question of exploitation is not as salient where a minor is seeking a test herself. (Of course, there is always the potential for exploitation, particularly where the information gained from testing is familial, and might reveal information about other family members. Health professionals must be alert to requests from competent minors that appear to be made under duress; a coerced consent is invalid, as consent must be voluntary in order to be legally effective (discussed further below)). Any physical risks from the genetic testing process are also so negligible as to be almost non-existent. On this construction of the benefit proviso, a minor of or over the age of sixteen is only restricted from consenting to treatment or procedures that are for another person's benefit, rather than for her own benefit. The existence or lack of a clinical benefit to the minor is irrelevant in terms of the benefit proviso when the procedure or treatment is sought for the minor's own purposes or interests. The phrase 'carried out on the child for the child's benefit' means carried out for the child, as opposed to carried out for another.

12 *Adams on Criminal Law* (online), Brookers Ltd, Wellington, CA61.05, accessed 21 June 2006.

13 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, 51, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996.

14 For example, ss 4 and 5 of the Care of the Children Act 2004 regarding the paramountcy of the child's best interests and welfare in care or guardianship matters relating to children.

15 P.D.G. Skegg, 'Consent to treatment: introduction', pp 145-169, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, p 165.

16 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 91. McDowell argues that 'analysis of what constitutes "beneficial" treatment may also incorporate argument similar to that applied to the "best interests" test.' 'Best interests of the child' does not refer solely to a child's best medical interests. In *Re Norma*, Tompkins J recognised that 'a child's welfare is bound up with his or her family [and that] if a course of action is likely to cause serious distress and disruption within a family, that too is a factor which must bear on the welfare of the child and therefore weigh with the Court.' *Re Norma* [1992] NZFLR 445, per Tompkins, J. A procedure that is non-therapeutic can be in a minor's 'best interests' in certain circumstances (for

example, see the discussion on *Re Y (adult patient) (transplant: bone marrow)* (1996) 35 BMLR 111) in the section on *Genetic Testing of Children who Cannot Give a Valid Consent*). Likewise, a non-therapeutic procedure can be carried out for a minor's 'benefit'. Indeed in the United States, judges have resolved that organ donation between siblings can be in the 'best interests' of the donor (despite the fact that organ donation is not clinically therapeutic) because of the psychological and social benefits that would flow from the donation (and the harms that could flow from not allowing the donation). Susan Zinner (2004) 'Cognitive Development and Pediatric Consent to Organ Donation' *Cambridge Quarterly of Healthcare Ethics* 13, 125-132, 125, referring to the examples of: *Strunk v. Strunk*, 445 S. W. 2d. 145 (Ky. 1969); *Hart v. Brown*, 29 Conn. Supp. 368, 289 A. 2d. 386 (1972); and *Little v. Little*, 576 S. W. 2d. 493 (Tex. Civ. App. 1979), cited in: FA Rozovsky *Consent to Treatment: A Practical Guide*, 2nd ed. Little, Brown, Boston, 1990:621–2. On this interpretation of 'best interests' one would imagine that a competent minor could consent to something like 'non-therapeutic' genetic testing as a beneficial procedure which carries significantly fewer clinical risks than organ donation.

17 In the section on 'Benefits and harms'.

18 See Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 558, for further argument, in relation to *Gillick* competent minors, that a competent autonomous decision should be respected, regardless of how 'unreasonable or undesirable' it may appear to others. 'It should not be dependent on or curtailed by a doctor's opinion of the individual's best interests.'

19 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, p 190. Skegg refers to *Re A (Children) (Conjoined Twins: Surgical Separation)* 2001] Fam 147 (CA), and *Simms v Simms* [2003] 1 All ER 699; [2003] Fam 83; [2004] Lloyd's Rep Med 236 as examples.

20 The non-medical benefits of the various kinds of genetic testing are discussed above in the section on 'Benefits and harms'.

21 [1985] 3 All ER 402 (HL), [1986] 1 A.C. 112 (H.L.(E.)).

22 A third strand of argument was raised, regarding whether a doctor who gave such advice or treatment to a girl under sixteen without her parents' consent would incur criminal liability, which related to the laws surrounding the age of consent and aiding and abetting the commission of unlawful sexual intercourse. This issue does not have the same relevance for the purpose of this report.

23 Fraser LJ reinforced his view with reference to Blackstone's Commentaries: 'The power of parents over their children is derived from … their duty.' *Blackstone's Commentaries* (1 Bl Com (17th edn, 1830) vol I, chs 16 and 17).

24 Per Lord Fraser, p 410.

25 Fraser LJ referred to previous House of Lords' decisions as precedents for these propositions. 'In the case of a very young child, it would not have the understanding or the intelligence to give its consent, so that absence of consent would be a necessary inference from its age. In the case of an older child, however, it must, I think be a question of fact for a jury whether the child concerned has sufficient understanding and intelligence to give its consent …' (at 411, quoting *R v D* [1984] 2 All ER 449 at 457, per Lord Brandon (a case about a father kidnapping his child)). '… the legal right of a parent to the custody of a child ends at the eighteenth birthday and even up till then, it is a dwindling right which the courts will hesitate to enforce against the wishes of the child, the older he is. It starts with a right of control and ends with little more than advice' (at 412, quoting from *Hewer v Bryant* [1969] 3 All ER 578 at 583, per Lord Denning (a case involving control and custody)).

26 Lord Fraser offers a series of matters that a doctor must be satisfied of before proceeding with contraceptive advice or treatment without the consent of a minor's parents. The following guidance has subsequently become known as the 'Fraser Guidelines'. 'But there may well be cases … where the girl refuses to tell the parents herself or to permit the doctor to do so and in such cases the doctor will, in my opinion, be justified in proceeding without the parents' consent or even knowledge

provided he is satisfied on the following matters: (1) that the girl (although under 16 years of age) will understand his advice; (2) that he cannot persuade her to inform her parents or to allow him to inform the parents that that she is seeking contraceptive advice; (3) that she is very likely to begin or continue having sexual intercourse with or without contraceptive treatment; (4) that unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer; (5) that her best interests require him to give her contraceptive advice, treatment or both without the parental consent.' (Per Lord Fraser, p 413).

27 *Blackstone's Commentaries* (1 Bl Com (17th edn, 1830) vol I, chs 16 and 17), *R v D* [1984] 2 All ER 449, *Hewer v Bryant* [1969] 3 All ER 578.

28 Whilst Lord Brandon also dissented, his dissent turned largely on the issue of whether it was against public policy for doctors to advise and treat minors under 16 in relation to contraceptive matters given that '16 is the age of girl below which a man cannot lawfully have sexual intercourse with her' (at p 431). He examined the criminal law provisions in relation to sexual activity with girls under the age of sixteen and concluded that it would be against public policy for anyone (whether parents, doctors, social workers or others) to promote, encourage or facilitate the commission of such an act (at p 429). To give a girl contraceptive treatment would remove one of the major inhibitions against the having of sexual intercourse between a man and a girl under 16: the risk of an unwanted pregnancy (at 430). This particular treatment of the issue (focussing on the unlawfulness of the sexual activity) is not of great relevance to the thrust of this section of the Report and will not be discussed further.

29 See how members of the New Zealand judiciary have referred to *Gillick* in notes 58-66 to the discussion of cases on pps 14-15. We say 'in New Zealand at least' because the 'Fraser Guidelines' (see n 26, and p 413 of *Gillick*) and '*Gillick* competence' are frequently used interchangeably in England (see Robert Wheeler (2006) 'Gillick or Fraser? A plea for consistency over competence in children' *BMJ* 332, 807- (online version). Additionally, Elliston has argued that 'English law appears to have developed in accordance with Lord Fraser's judgement by which she means that a best interests approach is taken to medical decision-making for minors, rather than an approach which respects the minor's autonomy. See Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children' in Sheila McLean (Ed.) (1996) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England.

30 This formulation is also supported by the headnotes to the official reports of the case: 'a girl under the age of sixteen had the legal capacity to consent to medical examination and treatment, including contraceptive treatment, if she had sufficient maturity and intelligence to understand the nature and implications of the proposed treatment.' *Gillick v West Norfolk and Wisbech Area Health Authority and Department of Health and Social Security* [1986] 1 A.C. 112 (H.L.(E.)), at 113, G and ' … parental rights … yielded to the child's right to make his own decisions when he reached a sufficient understanding and intelligence to be capable of making up his own mind.' *Gillick v West Norfolk and Wisbech Area Health Authority and Another* [1985] 3 All ER 402 (HL). At 403, c.

31 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, p 193.

32 See discussion of these cases at pp 14-15, and in notes 58-67.

33 *Re SPO* 3/11/05, Judge Ullrich QC, FC Wellington FAM-2004-085-1046.

34 See *Re R (a minor)* [1991] 4 All ER 177 in which the English Court of Appeal held that a 'Gillick competent' child *or* one over the age of sixteen had a power to consent, but that this was concurrent with that of a parent or guardian. A health professional would not be liable for treating in the face of child's refusal to consent if consent had been given by somebody else with parental responsibility (or the Court). *Gillick* was distinguished on the basis that it concerned only a child's independent right to consent, and did not decide that a competent child had the right to *refuse* treatment. A child's right to refuse treatment could be trumped by an adult's right to consent on their behalf. It is difficult to reconcile the decision in *Re R (A Minor)* with the very clear statements from the Law

Lords in *Gillick*: '… I would hold that as a matter of law the parental right to determine *whether or not* (emphasis author's own) the minor child below the age of sixteen will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. (Per Lord Scarman at 423).' The Court of Appeal took the opportunity to restate their findings in *Re W (A Minor)* [1992] 3 WLR 758, which concerned a sixteen-year-old girl refusing treatment for anorexia. In that case the Court held that s 8 of the Family Law Reform Act 1969, which stated that minors of sixteen or more could consent to surgical, medical and treatments as if they were of full age, did not give such minors an absolute right to refuse treatment: it simply protected the doctors from prosecution by allowing them to consent as if they were of full age. In *Re M (child: refusal of medical treatment)* [1999] 2 FCR 577 a 15 and half year old girl had her refusal to consent to a heart transplant overturned by the Court, because the Judge believed it was in her best interests to have the transplant. Johnson J referred to the decision in *Re W* for the proposition that a minor's refusal to consent to treatment could not override a consent given by a parent or Court (and in this case both the parents and the Court gave their consents).

35 Rebecca Opie and Clarke Willmott *Competent children, medical consent and their best interest*, accessed from http://familieslink.co.uk/pages/law_gillick_competence.htm on 30 May 2006.

36 Particularly in respect of the strong statements made by Lord Scarman about parental rights to determine *whether or not* a child below the age of sixteen will have medical treatment terminating if and when the child achieves a sufficient understanding and intelligence to enable her to understand fully what is proposed.

37 For example, see the UK Department of Health Guidance to Health Professionals *Seeking Consent*: working with children (2001), p 5 (refers explicitly to 'Gillick competence'), available at www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf (accessed 7 June 2006), and the BMA Consent Tool Kit Second Edition, February 2003, Card 5 – assessment of competence, and Card 7 – children and young people, accessed on 7 June 2006 from www.bma.org.uk/ap.nsf/Content/consenttk2.

38 The principle that whilst those under the age of sixteen may be *Gillick* competent to consent to treatment, any refusal of treatment by such a minor can be overridden sits more agreeably with s 8 of the UK Family Law Reform Act (FLRA) 1969. Section 8 states that the consent of a minor who has attained the age of sixteen shall be as effective as it would be if she were of full age. It also states that nothing in the section should be construed as making ineffective any consent which would have been effective had the section not been enacted, preserving the parental right to consent on behalf of a minor child. Note, that unlike s 36(1) of the New Zealand COCA 2004, the provision does not give such minors effective refusal of consent to treatment. Thus, a sixteen or seventeen-year-old minor's refusal to consent to treatment in the United Kingdom is not as effective as it would be as if she were of full age; it can be overridden by the consent of a guardian (s 8(3) FLRA 1969).

39 Although note that the Code of Health and Disability Services Consumers' Rights (discussed further below) states that all health and disability services consumers are to be presumed competent unless there are reasonable grounds to believe otherwise (Right 7(2)).

40 Rob Potter (2004) 'Consent quiz: how well would you do?' in *Psychiatric Bulletin*, 28, 91-93, p 92 (online version), referring to I McCall-Smith (1992) Consent to treatment in childhood. *Archives of Disease in Childhood*, 67, 1247-1248, and J Pearce (1994) Consent to treatment during childhood. The assessment if competence and the avoidance of conflict. *British Journal of Psychiatry*, 165, 713-716.

41 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996, referring to K. Norrie 'The Age of Legal Capacity (Scotland) Act 1991' *Journal of the Law Society of Scotland,* 36, November 1991, 111-13.

42 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996, referring to J.K. Mason and R.A. McCall Smith, *Law and Medical* Ethics, 4th ed., Butterworths, London, 1994, ch. 10, at 229.

43 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, 34, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996.

44 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, 34, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996.

45 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996, referring to I. Kennedy 'The Doctor, the Pill and the 15-Year-Old-Girl' in *Treat me Right*, Oxford, Clarendon Press, 1994, ch. 5 for this point.

46 Sarah Elliston 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children,' pp 29-55, 42, in Sheila McLean (Ed.) *Contemporary Issues in Law, Medicine and Ethics* Dartmouth Publishing Company Ltd, England, 1996. Elliston goes on to state that 'While setting an arbitrary age for such reasons as ability to vote is acceptable, since the administrative difficulties involved in questioning every citizen in order to establish their competence for enfranchisement would be practically insurmountable, the same is not true where decisions about the management of health of an individual are concerned' (pp 42-43).

47 [1992] 3 WLR 758.

48 Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health*, Ministry of Health, Wellington, 1998 (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC). Potter, J in the case of *R v Laufau and Laufau* (High Court, Auckland, 23/8/00 and 2/10/00, T.000759) 'seemed to suggest that someone under the age of 16 might be able to give an effective refusal of consent, but then seemed to resile from that approach when passing sentence.' (P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, p 193.) Mr and Mrs Laufau were convicted of failing in their legal duty to provide the necessaries of life for a child under the age of sixteen (s 152 Crimes Act 1961), and acquitted of manslaughter. Their thirteen-year-old son Tovia had been diagnosed with a bone cancer in his leg. Despite being informed that he would die without treatment, Tovia refused treatment, and his parents acceded to his wishes. In summing up, Potter J stated that: 'The defence claim that Tovia's choice not to have treatment is an informed choice and that in abiding by that choice, his parents … acted with lawful excuse. You will need to consider and decide whether Tovia was capable of making an informed choice not to have medical treatment, if you accept the evidence of the family, that indeed was his choice. … You have heard Mr Hogan refer to the case of *Gillick* which was a decision of the House of Lords. The important thing about the *Gillick* decision is that it recognises that age is not the only determinant in deciding whether a person is capable of giving informed consent. … If you decide that Tovia was capable and competent to make an informed choice and you accept the evidence of the family as to what that choice was, you must consider that factor along with all other factors that you find proved …' [paras 31-33]. 'Age is not the final determinant; the fact that Tovia was under the age of sixteen does not prevent him from making an informed choice. That must be judged on his competence and his understanding of the situation.' [para 48]. Surprisingly, no mention appears to have been made in counsels' arguments, in summing up, or in the sentencing comments of any right of Tovia to refuse medical treatment pursuant to the New Zealand Bill of Rights Act 1990 (see M Woolford *R v Laufau* [2001] *Journal of the Auckland Medico-Legal Society* 19). However, in summing up for the jury, Potter J makes no mention of the English cases of *Re R (a Minor)* [1991] 4 All ER 177 or Re *W (a Minor)* [1992] 3 WLR 758 or a higher standard of competence being required of minors under the age of sixteen to refuse medical treatment, implying (as Skegg has commented, at 193) that such minors might be able to give effective refusal to consent. And yet in sentencing, Potter J had this to say at para. 15: 'The law recognises that young people are not necessarily capable of exercising the maturity necessary to take life and death decisions. Consequently, … the law imposes on their parents or their

caregivers the legal duty to provide the necessities of life so that their lives can be protected and not exposed to danger. It will not therefore usually be a lawful excuse for the parents to accede to the wishes of a child when it comes to a matter of life and death. The jury did not accept that Tovia's wish that he not be returned to hospital, provided a lawful excuse that should have priority over the legal duty placed on Mr and Mrs Laufau to provide their son with the necessaries of life, namely medical treatment. The duty the law imposes on parents and caregivers is greater and stronger than the wishes of their children, no matter how sincerely and strongly they might be expressed, and no matter how strong may be the wish or will of the parents to accede to the child's bidding. It is one matter for an adult person will full mental faculties to exercise a right to elect not to undergo medical treatment. It is quite a different matter for the parents or caregivers of a child who carry the legal duty and responsibility to ensure that child has the necessaries of life, to determine that the child shall not have medical treatment when medical treatment is necessary to protect his life. …' The *Laufau* case demonstrates that even if a child refuses treatment, and persuades his parents not to insist on treatment, the parents may still be held criminally liable. However, juries may doubt the competency of a child who dies as result of his medical decision (Jeannie Bayly 'Informed Consent and Paediatricians', accessed on 26 May 2006 from www.conferenz.co.nz/2004/library/b/bayly_jeannie.html), and it seems clear that the jury and indeed the judge also doubted Tovia's competency in this case (see discussion below on the New Zealand Bill of Rights Act 1990).

49 *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_04.html, accessed 21June 2006. See discussion on the Code of Health and Disability Services Consumers' Rights, below this section.

50 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 193 in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

51 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 194 in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

52 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 193 in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

53 Section 15: Guardianship defined— For the purposes of this Act, 'guardianship' of a child means having (and therefore a 'guardian' of the child has), in relation to the child,— (a) all duties, powers, rights, and responsibilities that a parent of the child has in relation to the upbringing of the child: (b) every duty, power, right, and responsibility that is vested in the guardian of a child by any enactment: (c) every duty, power, right, and responsibility that, immediately before the commencement, on 1 January 1970, of the Guardianship Act 1968, was vested in a sole guardian of a child by an enactment or rule of law.

54 Mark Henaghan *Family Law Outline,* 'Guardianship', Faculty of Law, University of Otago, Dunedin, 2006, p 11.

55 Mark Henaghan *Care of Children* LexisNexis NZ Ltd, Wellington, 2005, p 20. Atkin lamented that the COCA 2004 did not make as much progress in terms of child rights as it could have, and that s 36 was limited by the 'arbitrary age limit of 16': 'Noticeably absent is any attempt to adopt … *Gillick*. … This judgment was a major strike in favour of children's rights and arguably it applies in New Zealand.' Bill Atkin 'The Care of Children Bill – Alright but only as far as it goes', accessed 26 May 2006 from www.conferenz.co.nz/2004/library/a/atkin_bill.htm. Shortly after the decision was handed down Atkin argued for the applicability of the general statements in *Gillick* to New Zealand. W R Atkin *A blow for the rights of the child, Mrs Gillick in the House of Lords*, Family Law Bulletin, 35-39 (1985). He contended that while the Act was a code it did not provide for every eventuality and the definition of 'guardianship' did not 'purport to cover every circumstance.' W.R. Atkin *A blow for the rights of the child, Mrs Gillick in the House of Lords*, p 36. Atkin further contended that while some may argue that s 14 (review of a guardian's decision or refusal to give consent) implied that 'children,

even in their late teens, have no independent decision making power and are subject to dominant parental power,' the section did not set out at all when a parent or guardian's consent was essential in law. Thus the importation of rules from *Gillick* was not inconsistent with the machinery provided to review a parent's decision. The definition of 'guardianship' referred to a 'right of control over the upbringing of a child,' not to a right of 'exclusive or complete control.' It further did not address the relationship between parents and children: it did not rule out the possibility that as a matter of law children may have independent decision-making powers depending on their age and maturity. The definition deals more particularly with other contexts: a person who is not a guardian of a child not having rights over a child's upbringing (Atkin, p 36). Atkin argues that '… guardianship includes all rights, powers and duties in respect of the person and upbringing of a child that were at the commencement of this Act vested by any enactment or rule of law in the sole guardian of a child.' In other words, the common law is saved by an express provision of the kind envisaged by s 33. It is true that because of the word 'includes' guardians may have more rights, powers and responsibilities than were available at common law. But where the common law has clearly limited those rights, then that limitation prima facie should continue to exist. *Gillick* represents judicial lawmaking and is response to social and technological change. But in strict theory, Judges in formulating the common law are saying in clear words what was thitherto left unsaid. Thus it is submitted that *Gillick* articulates aspects of rights, duties and responsibilities of guardians (and parents) as they were 'at the commencement of this Act. …The conclusion therefore is that the general level of statements in *Gillick* apply in New Zealand. They are consistent with the statutory scheme in the Guardianship Act 1968" (Atkin, p 37). Given that the corresponding provision of the COCA 2004 (s 13 replaces 33 of the Guardianship Act 1968) is essentially the same, Atkin's argument is equally useful today. Atkin then questioned whether the existence of s 25 of the GA 1968 (equivalent to s 36 of the COCA 2004) affected the application of *Gillick*. Section 25(5) expressly preserved any common law rules whereby (a) no consent or no express consent was necessary; (b) the consent of the child in addition to any other person is necessary; and (c) the consent of any other person instead of the consent of the child is sufficient (Atkin, p 37). 'This subsection does not expressly refer to any rule whereby the consent of the child alone will be sufficient, but arguably a rule about the non-necessity of parental consent could fall within exception (a). Subsection 5(a) is silent on whose consent need not be obtained. It is possible to argue that in the context of a section which deals primarily with proxy consent, subs 5(a) embraces, inter alia, the *Gillick* kind of situation. … no consent from the parents is necessary because the child can give sufficient consent. There is a further argument however to justify the co-existence of *Gillick* with s 25. Section 25(3), which sets out the authority for proxy consent, commences with the words "where the consent of any other person … is necessary or sufficient." It will be noticed that the subsection does not spell out the circumstances in which another person's consent is indeed necessary or sufficient. This is a matter left to the Courts and the determination of the House of Lords can been seen as filling the vacuum which has long existed on this question' (Atkin, pp 37-38). Again, the relevant law remains essentially the same under the COCA 2004, and thus the argument retains its validity in the present day.

56 *Consent in Child and Youth Health*, Ministry of Health, Wellington, 1998, p 31 (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.

57 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 193, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

58 *Ausage v Ausage* [1997] NZFLR 72. In a case concerning an application by a sixteen-year-old girl for a final protection order against her father, Judge Somerville was 'of the view that although a parent still has powers of correction of a sixteen-year-old child, that would involve the application of force on only the rarest of occasions.' Judge Somerville adopted the following passage from the judgment of Lord Fraser in *Gillick v West Norfolk AHA* [1986] AC 112 at 171 in support of her view: 'It is, in my view, contrary to the ordinary experience of mankind … to say that a child or young person remains in fact under the complete control of his parents until he attains the definite age of majority

… and that on attaining that age he suddenly acquires independence. In practice most wise parents relax their control gradually as the child develops and encourage him or her to become increasingly independent. Moreover, the degree of parental control actually exercised over a particular child does in practice vary considerably according to his understanding and intelligence and it would, in my opinion, be unrealistic for the Courts not to recognise these facts.'

59 *Hyde v CIR* [2000] NZFLR 385. In a case concerning an application by young person for payment of child support from her parents, Judge Carruthers stated that 'In further support of his submission Mr Bourne refers amongst other cases to the well-known English authority of *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 which established in very clear terms the capacity of a child or young person to make decisions for himself or herself.'

60 *Ryding v Turvey* [1998] NZFLR 313. In a Hague Convention case Judge Inglis QC stated that 'I am satisfied on the psychologist's evidence that Adam and Simon do indeed object to returning to England. The reasons for their respective objections are valid and well-founded both from the individual perspective of each and also objectively. I am satisfied that each has attained an age and level of maturity at which it is appropriate to take account of his views. … The views of Adam and Simon are not however determinative of the position and I have to take the next step of considering how far they should affect me. I have on this issue found helpful guidance in the classic case *of Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 (HL), which has nothing to do with the Hague Convention but everything to do with the rights of the child and the independence of a teenager. Lord Scarman (at 186) expressed the principle that ". . . parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision." Here both boys have expressed clear and consistent objections to returning to England and are shown to have been capable of making up their own minds on the matters which are basic to the objections which each has expressed.'

61 *D-GSW v MJB* [1995] NZFLR 692 (High Court) and *MJB v D-GSW* [1996] NZFLR 337 (Court of Appeal). Delivering the judgment of the Court of Appeal, Gault, J stated that 'The upbringing of children extends to making decisions for them as to health and medical treatment. That is a right long recognised under the common law in any event: *Gillick v West Norfolk AHA* [1986] 1 AC 112 though, as that case makes clear, it was never absolute. As was pointed out particularly by Lord Scarman (184-5) the scope of parental rights is reflective of parental duties towards children.'

62 *Re B (children)* [1992] NZFLR 726. In a case concerning whether family reunification was in the best interests of children who had been placed in foster care, Judge Inglis QC stated: 'It cannot be assumed that the return of a child to his or her family (in this case, on any view of the matter, to only part of the family) will automatically be in the child's best interests and welfare simply because they are family. That gives the blood tie priority over the child's welfare and interests. That is not permissible, because it makes the blood tie and parental and family rights, rather than the child's welfare and interests, the deciding factor. Parental and family rights are relevant only to the extent that they are exercised for the welfare and interests of the child: *Pallin v Department of Social Welfare* [1983] NZLR 266 (CA); *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 (HL); *Director General of Social Welfare v L* [1990] NZFLR 125, 137 (CA, per Hardie Boys J). While each of these cases was decided in a different statutory context, there is nothing in the Children, Young Persons, and Their Families Act to indicate a legislative intention to diminish the established legal principle laid down in them.' In another case concerning a care and protection plan review (*Re the P Children (No 2)* (1992) 9 FRNZ 93), Judge Inglis QC also referred approvingly to Lord Scarman's statements about dwindling parental rights and children's rights to make their own decisions when they reach sufficient understanding and intelligence. 'Though the principle is clear and applies as a general principle in each case where the relationship of child and parent falls to be considered, each case must of course depend in the end on its own particular circumstances' (p 107). On the facts before Judge Inlglis QC, relating to the educational deprivation of children who had

been brought up by 'staunch Seven Day Adventists,' 'the parents' right of control over the two eldest boys' lives is a dwindling right and those boys are entitled to a voice in their future' (p 108).

63 *R v Hemi* [1986] 2 NZLR 116. In deciding to admit evidence from a detective about a fifteen-year-old's confession of murder, Jeffries, J stated that 'Defence counsel concentrated on the chronological age of the accused and that undoubtedly, as I have said, is an important indicator. However, in my view the Court is obliged to make that only one aspect, although an important one, in the environment in which we are now living. As the age of majority has fallen with earlier maturing physically and mentally of young people, so assessments of maturity at lower ages has to be reconsidered. At 15 a person may join the workforce. Gillick's case [1985] 3 All E.R 402 in the House of Lords has faced the changing environment. A Court is required in circumstances such as these to assess, as best it is able, the level of maturity of this accused.'

64 *Director-General of Social Welfare v R* (1997) 16 FRNZ 357. At p 368 Judge P von Dadelszen said 'Everyone who gave evidence only confirmed my view that R's current level of maturity is such that her own wishes must be given a considerable amount of weight. The leading authority on the issue of the child's wishes is that of the House of Lords in *Gillick* … where Lord Scarman said that parental rights yield "to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable or making up his own mind on the matter requiring decision"." Judge P von Dadelszen concluded that 'there should be no order, the effect of which will compel R to see her mother against her wishes. Such a view acknowledges this young person's right to control this aspect of her life and it is plainly in her best interests. I think it entirely inappropriate that this Court should be seen to be foisting something on her against her will. That would send quite the wrong message to this mature almost 15-year-old girl: that, not only is she not listened to, or, even if she is, her wishes are not respected' (at p 371).

65 *R v Laufau and Laufau* 23/8/00 Potter J HC Auckland T000759. See note 48 for a discussion of the application of *Gillick* in this case.

66 *Re SPO* 3/11/05, Judge Ullrich QC, FC Wellington FAM-2004-095-1046.

67 *Re SPO* 3/11/05, Judge Ullrich QC, FC Wellington FAM-2004-085-1046.

68 Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992, accessed from www.moh.govt.nz/moh.nsf/0/BA365913B5EA0E334C2568AF001733A6/$File/GuidelinesCAT92.pdf on 20 June 2006.

69 Available at www.nzma.org.nz/about/ethics/codeofethics.pdf.

70 *Consent in Child and Youth Health*, Ministry of Health, Wellington, 1998, p 12 (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC).

71 Skegg (P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 195, note 112, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006) states that 'the Code of Rights goes beyond the common law … in providing a presumption whereby every consumer (seemingly a child as well as adult) must be presumed to be competent unless there are reasonable grounds for believing that the consumer is not competent (right 7(2)).' See discussion of the Code of Health and Disability Services Consumers' Rights directly following this section.

72 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 195, note 112, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

73 Skegg (P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 195, note 113, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006) refers to *Auckland Healthcare Services v Liu* 11/7/96, Tompkins J, HC Auckland M812/96 in which the 'High Court Judgment seemingly rejected the notion that someone under the age of 16 years could give a legally effective consent' (Skegg, p 193) and the case of *R v Laufau* 23/8/00, Potter J, HC Auckland T000759, and 2/10/00, in which the 'judge directed a jury in terms that seemed to suggest that someone under the age of 16 might be able to give a legally effective refusal of consent, but then seemed to resile from that approach when passing sentence' (Skegg, p 193).

74 Skegg (P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 195, note 114, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006) refers to *Re SPO* 3/11/05, Judge Ullrich QC, FC Wellington FAM-2004-095-1046.

75 P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 195, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

76 Pursuant to the Health and Disability Commissioner Act 1994 (HDC Act).

77 In accordance with cl 1(1) of the Code every consumer has the rights in the Code. Consumer is defined (cl 4) as a health consumer or a disability services consumer, and includes (for the purposes of certain rights) a person entitled to give consent on behalf of that consumer. Health consumer is defined in the HDC Act 1994 as including 'any person on or in respect of whom any health care procedures is carried out.' The phrase 'a person entitled to give consent on behalf of that consumer' is not further defined in either the Code or the HDC Act, but is so in other legislation and common law (e.g. COCA 2004).

78 Skegg (P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, 195, note 112, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006) notes that the presumption in the Code goes beyond the common law principle espoused in *Gillick* and that 'this provision is for the purposes of Code liability – although it may well have a knock-on effect on disciplinary liability' (p 191).

79 Health and Disability Commissioner's Opinion: www.hdc.org.nz/files/hdc/opinions/01hdc12269.pdf, accessed 13 April 2007. In such cases the parents or guardians of young patients have many of the rights referred to in Right 7, and others relating to communication, information and complaints (These will be discussed further below in relation to genetic testing of children too young to consent on their own behalves). Additionally, right 7(3) directs that even where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.

80 Annie Fraser 'The Informed Consent Process and the Application of the Code to Children' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 49, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

81 See Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework', Annie Fraser 'The Informed Consent Process and the Application of the Code to Children', and Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006, and *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_04.html, accessed 21 June 2006.

82 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 5, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

83 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 12, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

84 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 50, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

85 Annie Fraser 'The Informed Consent Process and the Application of the Code to Children' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 49, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

86 General Practitioner, Dr C and Nurse, Ms D, (Case 01HDC02915), 6 March 2002, accessed from www.hdc.org.nz/complaints/casenotes?01HDC02915 on 16 April 2007.

87 General Practitioner, Dr C and Nurse, Ms D, (Case 01HDC02915), 6 March 2002 accessed from www.hdc.org.nz/complaints/casenotes?01HDC02915 on 16 April 2007.

88 Indeed, the Health and Disability Commissioner has argued that where a minor under the age of sixteen was found competent, practitioners could respect their right to refuse treatment based on the right to refuse in the NZBORA 1990. (Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC).

89 The issue of how competency is assessed and whether a greater degree of competence is required in order to consent to genetic testing is discussed below under the heading 'Competence and Genetic Testing Of Minors.' The Code supports the right of both the statutorily competent 16 or 17 year old minor and the *Gillick* competent minor under the age of sixteen to consent or refuse consent to genetic testing. Notably, in the context of the code, competent minors can give informed consent to medical services without the proviso (seen in s 36(1), COCA 2004) that the procedure must be for the benefit of the minor. This supports the purposive approach to interpreting s 36(1) which is aimed at respecting the autonomy of 16 and 17 year olds.

90 According to s 2 of the Health and Disability Commissioner Act 1994: 'Informed consent', in relation to a health consumer on or in respect of whom there is carried out any health care procedure, means consent to that procedure where that consent: (a) Is freely given, by the health consumer or, where applicable, by any person who is entitled to consent on the health consumer's behalf and; (b) Is obtained in accordance with such requirements as are prescribed by the Code.

91 Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 41, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC).

92 Choice means a decision: to receive services; to refuse services; or to withdraw consent to services (cl 4 – Definitions).

93 Much has been written on tailoring the information given to the recipient to that person's level of understanding and to what might be regarded as important to that particular person. For example, the Australian case of *Rogers v Whitaker* (1992) 175 CLR 479 found that a patient should have been informed of a one in 14, 000 chance that she could lose her sight in the eye operated on as result of the proposed surgery, because she had already lost her sight in the other eye; this kind of information may well have affected her decision whether to undergo the surgery. However, health professionals must also be guided by the general rule regarding what a reasonable person would expect to be told.

94 Annie Fraser 'The Informed Consent Process and the Application of the Code to Children' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 50, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

95 Annie Fraser 'The Informed Consent Process and the Application of the Code to Children' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 50, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

96 Except where safety may be compromised or another consumer's rights may be unreasonably infringed.

97 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part I: An Introduction to the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part1.html.

98 Section 4 states that no Court shall: (a) hold any provision to be impliedly repealed or revoked, or to be in any way invalid or ineffective; or (b) decline to apply any provision of an enactment, by reason only that the provision is inconsistent with any provision of the NZBORA 1990.

99 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part II: Initial Considerations When Applying the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part2.html.

100 [1992] 1 NZLR 363, 373.

101 It is this competency requirement that implies that the judge and jury in the *Laufau* case (see discussion above regarding *Gillick* competence and the right to refuse, and the discussion of the *Laufau* case in note 48) did not consider Tovia Laufau competent to refuse treatment for the bone cancer in his leg. If he had been considered competent and thus entitled to rely upon his s 11 right to refuse treatment, then his parents presumably could not have been held criminally liable in respect of his death.

102 [1992] 1 NZLR 363, 373.

103 Austin has previously argued that 'the value of *Gillick* for assessing whether restricting the right of children to refuse medical treatment is a justified limitation is the majority speeches' emphases, not only on children's developmental capacity to understand the decision, but, as significantly, on the importance of such decisions to children's relationships with and within their families. For many children, there will be "moral and family questions" impacting on many decisions. It is only appropriate that the law should acknowledge them. Principles underlying the application and limitation of the right contained in section 11 should, as far as possible, recognise children's rights and their relationships. If a child's understanding of the decision includes an understanding of its implications for the child's family, there seems to be no reason why section 11 should be limited in cases concerning children. It is submitted that a child's right to refuse medical treatment should only be limited when a child lacks appreciation of the types of issues Lords Scarman and Fraser considered important when assessing *Gillick* competence.' We respectfully disagree with Austin's analysis. He focuses on the need for minors to understand 'moral and family questions' in order to be competent to exercise the s 11 right to refuse treatment. However, he bases his argument on the comments of Lords Scarman and Fraser in relation to moral and family issues related specifically to *contraceptive advice and treatment*. Lord Scarman gives the general principle of law in relation to minors and medical decision-making as 'parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is involved.' (p 423, *j*) before clearly saying 'When applying these conclusions to contraceptive advice and treatment ….', at which point he focuses on the significance of 'moral and family questions.' Likewise Lord Fraser, who states at p 409*e* 'provided the patient, whether a boy or a girl, is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express them validly and effectively and to authorise the medical man to make the examination or give the treatment which he advises.' Lord Fraser's focus on the desirability of a minor's parents being involved in her medical decisions, and his guidelines (at p 413), arise specifically in the context of contraceptive advice or treatment. There is no clearly identifiable support in the majority judgments for Austin's argument that a minor must be able to consider 'moral and family questions' to be considered *Gillick* competent to make other kinds of medical decisions, and by implication to exercise his or her right to refuse medical treatment pursuant to s 11 of the New Zealand Bill of Rights Act 1990.

104 Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC).

105 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part III: Rights and freedoms affirmed by the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part3.html.

106 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part III: Rights and freedoms affirmed by the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part3.html.

107 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part II: Initial Considerations When Applying the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part2.html.

108 Note that Skegg has argued (P.D.G. Skegg 'Capacity to consent to treatment', pp 171-203, in P.D.G. Skegg and Ron Paterson *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, at p 200) that 'If those under the age of sixteen are to be given an effective power to prohibit even life-saving treatment, this should be done by Parliament – which should, at the same time, make appropriate provision for the effect that such a right would have on the duties which the law currently imposes on parents and others.' Such clear legislative guidance may have aided the jury in the *Laufau* case (discussed above at note 48).

109 Although this is how it was interpreted in *Auckland Healthcare Services v Liu* (1996) High Court, Auckland, 11/7/96, M812/96.

110 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part II: Initial Considerations When Applying the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part2.html.

111 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part III: Rights and freedoms affirmed by the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part3.html.

112 Ministry of Justice *The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector*, Part III: Rights and freedoms affirmed by the Bill of Rights Act, accessed 14 June 2006 from www.justice.govt.nz/pubs/reports/2004/bill-of-rights-guidelines/part3.html.

113 Somalia, which is in a severe state of civil unrest, and the USA. New Zealand co-sponsored UNCROC in the UN but did not ratify it until 1993 (Robert Ludbrook *A New Zealand Guide to Children and the* Law Inprint, Lower Hutt, New Zealand, 1991).

114 UNCROC can be accessed by visiting www.unhchr.ch/html/menu2/6/crc/treaties/crc.htm. Note in particular articles 1, 2, 3, 4, 5, 6, 12, 13, 14, 16, 18, 19, 23, 24, 25, and 27. Further of the articles will also be relevant to certain family or medical situations.

115 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 5, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

116 Michael Freeman has referred to article 12 as the linchpin of UNCROC: M Freeman (1996) 'The Importance of a Children's Rights Perspective in Litigation', *Butterworths Family Law Journal* December: 84-90.

117 UN Committee on the Rights of the Child, General Comment No. 7 (2005) 41st session, 9-27 January 2006 [UN Doc.CRC/C/GC/7] *Implementing child rights in early childhood*, in *International Human Rights Reports*, Vol. 13, No. 2 Apr. 2006, pp 309-322, at p 311.

118 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 5, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

119 Other articles referring to the evolving capacities of children: 14; 31; 32; 37; and 40.

120 *Youth and the Law 2003*, A comprehensive guide to the law relating to young people from birth to adulthood, 3rd ed revised and updated by Marcus Pawson, Educational Resources for Legal Resources Trust, Wellington, NZ, 2002, p 4.

121 Article 4 of UNCROC requires that States Parties undertake all appropriate legislative, administrative and other measures for the implementation of the rights, and compliance is monitored pursuant to art. 44 of UNCROC. Legislation is supposed to comply with New Zealand's international obligations: when bids are made for Bills to be included in the legislative programme and priorities are being awarded, Ministers must confirm compliance with (and draw attention

to any aspects that have implications for or may be affected by) legal principles or obligations in a number of areas, including international obligations. And, when a Bill is subsequently submitted to the Cabinet Legislation Committee for approval for introduction, the Minister is required to confirm that the draft Bill complies with these legal principles and obligations. Consequently, UNCROC cannot be ignored by the legislators. See Helen Bellchambers *International Law and PGD* unpublished, Human Genome Research Project, Law Faculty, University of Otago, 2006, and the Cabinet Manual, accessed 15 June 2006 from www.dpmc.govt.nz/cabinet/manual/5.html. The Children's Commissioner must have regard to the Convention when exercising her functions and powers (Section 11(a) Children's Commissioner Act 2003). One of the purposes of the Children's Commissioner Act 2003 was to confer additional functions and powers on the Commissioner to give better effect in New Zealand to UNCROC (s 3(c)). Her general functions include: raising awareness and understanding of UNCROC; advancing and monitoring the application of UNCROC by State departments and other Crown instruments; and if there are issues in proceedings before any Court or tribunal that relate to UNCROC, to present reports on such issues on request (by the Court, tribunal, any party's counsel, or any counsel for the child) (s 12(1)(d), (f) and (g) of the Children's Commissioner Act 2003). The Human Rights Commission must report to the Prime Minister on the desirability of legislative, administrative, or other action to ensure better compliance with international human rights standards, pursuant to s 5(2)(k) of the Human Rights Act 1993.

122 Judge Ullrich QC, FC Wellington FAM-2004-085-1046, para 26.

123 Sheila A M McLean (1995) 'Genetic Screening of Children: The U.K. Position' *Journal of Contemporary Health Law and Policy* 12, 113, p 124.

124 www.m-w.com/dictionary/competent, accessed 5 September 2006.

125 The terms competence and capacity will be used interchangeably throughout this discussion – as they are by the New Zealand Ministry of Health (*Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC), United Kingdom Department of Health, and the British Medical Association (See the UK Department of Health Guidance to Health Professionals *Seeking Consent*: working with children (2001), available at www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf (accessed on 7 June 2006), and the BMA Consent Tool Kit Second Edition, February 2003, www.bma.org.uk/ap.nsf/Content/consenttk2, accessed 7 June 2006).

126 These two legal classifications of competency are referred to in Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC), and *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_04.html, accessed 21 June 2006.

127 Note that there are varying levels of competence: the Code allows health services consumers with diminished competence to make informed choices and give informed consent to the extent appropriate to his or her "level of competence" (Right 7(3)). Thus competence is not an 'all or nothing' concept.

128 *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_03.html, accessed 21 June 2006. 'The right of a competent adult to reject health-care treatment is not limited, but there may be some limits on the right to choose treatment. For example, this may be limited by decisions about distribution of scarce resources, and it may not extend to compelling health-care professionals to act against their own moral or professional convictions.'

129 For example, see Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005, (accessed on 17 September 2006 from http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf), Stephen Robertson and Julian Savulescu (2001) 'Is There a Case in Favour of Genetic Testing of Young Children' *Bioethics* 15:1, and Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576.

130 Ellen Wright Clayton (1997) 'Genetic Testing in Children' *The Journal of Medicine and Philosophy* 22: 233-251, p 244.

131 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 90 (citing S D Hawkins (1996) 'Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes' 64 *Fordham Law Rev* 2075 at 2120).

132 For example, *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC gives the following examples (p 15): '(a) In emergencies, where an appropriate person cannot be found to give consent, health care professionals can – and have an obligation to – provide relevant treatment (common law and Crimes Act 1961). (b) Blood transfusions can be administered to children without consent in certain circumstances (s. 126B Health Act 1956). (c) Some legislation allows for compulsory treatment, for example the Mental Health (Compulsory Assessment and Treatment) Act 1992. The Health Act 1956 and the Tuberculosis Act 1994 also contain provisions for compulsory examinations and treatment. (d) In situations where a person of any age (including children and young people) is suspected of having excess blood alcohol levels, blood specimens may be taken by a registered medical practitioner or "authorised person" without consent if required by an 'enforcement officer' (Transport Act 1962).' Bunney writing in the Australian context (L. Bunney (1997) 'The Capacity of Competent Minors to Consent to and Refuse Medical Treatment' *Journal of Law and Medicine* 5, 52) opines that a failure to obtain an informed decision does not found an action in battery (if a health professional treats a patient) but one in negligence – presumably because consent (albeit uninformed) has been given. She claims that judges often blur this distinction with regard to children and require that a child's consent can only be effective if she makes an informed decision, whereas an adult need only 'consent' to medical treatment in order for a health professional to treat. The clear statement in our Code that services can be 'provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise' indicate that informed consent is required by *all* competent consumers in order for health professionals to treat in the New Zealand context.

133 Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 41, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC) and Lois A Weithorn and Susan B Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, p 1590.

134 See G K Suthers, J Armstong, J McCormack, and D Trott (2006) 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder' *J Med Genet* 43: 665-670, accessed from http://jmg.bmjjournals.com/cgi/rapidpdf/jmg.2005.039172v1, on 4 August 2006. The authors argue that the provision of genetic risk information by a 'disinterested service', rather than by the affected family member gives family members the opportunity to make some separation between their emotional and genetic ties. When a family member discloses her genetic status to another family member, she has already demonstrated an interest in genetic testing that might not be shared by her relative.

135 Ellen Wright Clayton (1997) 'Genetic Testing in Children' *The Journal of Medicine and Philosophy* 22: 233-251, p 245.
136 Priscilla Alderson 'Talking to children – and talking with them,' pp 27-36, 34 in Angus Clarke *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.
137 Vic Larcher (2005) 'Consent, competence and confidentiality' *BMJ* 330, 353-356, 354.
138 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 82-83.
139 Ron Paterson 'Legal and ethical dilemmas' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 42, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC). Guardians can give informed consent on behalf of their minor children who are not capable of giving consent themselves (s 36 COCA 2004).
140 *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_04.html, accessed 21 June 2006.
141 L Bunney (1997) 'The Capacity of Competent Minors to Consent to and Refuse Medical Treatment' *Journal of Law and Medicine* 5, 52, referring to I. Kennedy and A. Grubb *Medical Law: Text with Materials* Second edition, Butterworths, London, 1994, p 121.
142 The health care provider must focus on the ability of the consumer to understand the information given: Annie Fraser 'The Informed Consent Process and the Application of the Code to Children' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 50, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.
143 Priscilla Alderson 'Talking to children – and talking with them,' pp 27-36, 34 in Angus Clarke *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.
144 Annie Fraser 'The Informed Consent Process and the Application of the Code to Children' in *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 50, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.
145 Barbara A. Bernhardt, Ellen S. Tambor, Gertrude Fraser, Lawrence S. Wissow, and Gail Geller (2003) 'Parents' and Children's Attitudes Toward the Enrollment of Minors in Genetic Susceptibility Research: Implications for Informed Consent' *Am J Med Genet* 116A:315-323, 316.
146 J.K. Mason and G.T. Laurie *Mason and McCall Smith's Law and Medical Ethics* Seventh Edition, Oxford University Press, Oxford, 2006, p 208.
147 Julia Binedell 'Adolescent requests for predictive genetic testing,' pp 123-132, 128, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.
148 Shoshanna Shiloh 'Decision-making the context of genetic risk,' pp 82-103, 92, in Theresa Marteau and Martin Richards (Eds.) *The Troubled Helix: Social and psychological implications of the new human genetics* Cambridge University Press, UK, 1996.
149 Julia Binedell 'Adolescent requests for predictive genetic testing,' pp 123-132, 128, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998. Michie and Marteau also argue that there needs to be more research about reasoning processes, and their variation, in adults. Susan Michie and Theresa M. Marteau (1996) 'Predictive genetic testing in children: The need for psychological research' *British Journal of Health Psychology* 1, 3-14, p 5.
150 Priscilla Alderson *Children's Consent to Surgery* Buckingham, Open University Press, 1993, p 153.
151 See, for example, Sonya Morgan, Joanne Dixon, Alexa Kidd, and Deborah McLeod (2003) 'Genetics and genetic testing: Questions, answers and case scenarios' *NZFP* 30, 6, 420-424, and Sonya Morgan, Deborah McLeod, Alexa Kidd, and Barbara Langford (2004) 'Genetic testing in New Zealand: the role of the general practitioner' *New Zealand Medical Journal* Vol 117, No 1206.
152 DC Wertz, JH Fanos, and PR Reilly (1994) 'Genetic Testing for children and adolescents: Who decides?' *JAMA* 1994; 272; 875-81, 878.

153 Stephen Robertson and Julian Savulescu (2001) 'Is There a Case in Favour of Genetic Testing of Young Children' *Bioethics* 15:1, 42.
154 Asaff Harel, Dianne Abuelo, M.D., and Alessandra Kazura, M.D. (2003) 'Adolescents and Genetic Testing: What Do They Think About It?' *Journal of Adolescent Health* 2003; 33: 489-494.
155 Asaff Harel, Dianne Abuelo, M.D., and Alessandra Kazura, M.D. (2003) 'Adolescents and Genetic Testing: What Do They Think About It?' *Journal of Adolescent Health* 2003; 33: 489-494. Although note that only 33 per cent in the high risk groups would 'definitely' or 'probably' want to be tested.
156 Asaff Harel, Dianne Abuelo, M.D., and Alessandra Kazura, M.D. (2003) 'Adolescents and Genetic Testing: What Do They Think About It?' *Journal of Adolescent Health* 2003; 33: 489-494.
157 Asaff Harel, Dianne Abuelo, M.D., and Alessandra Kazura, M.D. (2003) 'Adolescents and Genetic Testing: What Do They Think About It?' *Journal of Adolescent Health* 2003; 33: 489-494.
158 K Barlow-Stewart, L Burnett, A Proos, V Howell, F Huq, R Lazarus and H Aizenberg (2003) 'A genetic screening programme for Tay-Sachs disease and cystic fibrosis for Australian Jewish high school students' *J. Med. Genet.* 40; 45.
159 K Barlow-Stewart, L Burnett, A Proos, V Howell, F Huq, R Lazarus and H Aizenberg (2003) 'A genetic screening programme for Tay-Sachs disease and cystic fibrosis for Australian Jewish high school students' *J. Med. Genet.* 40; 45.
160 Asaff Harel, Dianne Abuelo, M.D., and Alessandra Kazura, M.D. (2003) 'Adolescents and Genetic Testing: What Do They Think About It?' *Journal of Adolescent Health* 2003; 33: 489-494, referring to JJ Mitchell, A Capua, C Clow et al. (1996) 'Twenty-year outcome analysis of genetic screening programs for Tay-Sachs and B-Thalassemia disease carriers in high schools' *Am J Hum Genet* 59; 793-8, and L McCabe (1996) 'Efficacy of a targeted genetic screening program for adolescents' *Am J Hum Genet* 59; 762-3.
161 S Michie, M Bobrow, and TM Marteau (2001) 'Predictive genetic testing in children and adults: a study of emotional impact' *J Med Genet* 38(8)**:**519-26, 523.
162 Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005, p 161, (accessed on 17 September 2006 from http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf).
163 Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005, p 192, (accessed on 17 September 2006 from http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf).
164 Barbara A. Bernhardt, Ellen S. Tambor, Gertrude Fraser, Lawrence S. Wissow, and Gail Geller (2003) 'Parents' and Children's Attitudes Toward the Enrollment of Minors in Genetic Susceptibility Research: Implications for Informed Consent' *Am J Med Genet* 116A:315-323, 316.
165 Barbara A. Bernhardt, Ellen S. Tambor, Gertrude Fraser, Lawrence S. Wissow, and Gail Geller (2003) 'Parents' and Children's Attitudes Toward the Enrollment of Minors in Genetic Susceptibility Research: Implications for Informed Consent' *Am J Med Genet* 116A:315-323, 319.
166 Barbara A. Bernhardt, Ellen S. Tambor, Gertrude Fraser, Lawrence S. Wissow, and Gail Geller (2003) 'Parents' and Children's Attitudes Toward the Enrollment of Minors in Genetic Susceptibility Research: Implications for Informed Consent' *Am J Med Genet* 116A:315-323, 320.
167 Barbara A. Bernhardt, Ellen S. Tambor, Gertrude Fraser, Lawrence S. Wissow, and Gail Geller (2003) 'Parents' and Children's Attitudes Toward the Enrollment of Minors in Genetic Susceptibility Research: Implications for Informed Consent' *Am J Med Genet* 116A:315-323, 320.
168 Barbara A. Bernhardt, Ellen S. Tambor, Gertrude Fraser, Lawrence S. Wissow, and Gail Geller (2003) 'Parents' and Children's Attitudes Toward the Enrollment of Minors in Genetic Susceptibility Research: Implications for Informed Consent' *Am J Med Genet* 116A:315-323, 320.
169 See Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 565-566.

170 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 566.

171 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 95, and Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 566: 'no child should ever be forced to exercise *Gillick* competence.'

172 Human Tissue Authority 'Code of Practice – Consent' Code 1, July 2006, p 11.

173 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551-576, 565-566.

174 *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, (available at www.paediatrics.org.nz/PSNZold/disputes_03.html) begins its discussion on assessing competence by presuming that 'age is a rough guide to competence.' 'Very young children are not competent to give consent to their own health-care in an informed manner. Most children under 10 also lack the competence to give informed consent. They are not usually able to make informed judgements about their own health and best interests beyond very simple and immediate issues. … Older children (10-14) are often, but not always, able to form reasonable judgements about what should happen to them. Treatment options should be explored with these children as well as with their parents, to determine the child's preferences and to understand the reasoning behind them. This enables determination of and fosters the child's decision-making competence. … from about 14 years old would be expected to have views and to have these respected. While legally still minors, such young people are likely to have sufficient maturity to be rightly accorded a strong say in their own treatment. They are frequently making decisions, with serious consequences for their future life and well being, in areas other than health-care.' In deciding that a 14 year old boy could and did give informed consent to his own tetanus immunisation, the Health and Disability Commissioner referred to what persons 'of that age' were able to understand: 'A young person of that age is well able to understand basic medical information and give consent to a vaccine injection.' *General Practitioner, Dr C and Nurse, Ms D,* (Case 01HDC02915), 6 March 2002, accessed from www.hdc.org.nz/complaints/casenotes?01HDC02915 on 16 April 2007. Likewise, in another statement about whether or not a minor was competent the Health and Disability Commissioner referred to the minor's age as a relevant feature: 'In light of Miss A's young age (10 years) and the nature of the decisions (consent to immunisation), there were reasonable grounds for Dr B to believe that she was not competent to make an informed choice and give informed consent (see right 7(2)).' See www.hdc.org.nz/files/pageopinions/01hdc12269.pdf.

175 ML Gillies, WL Parry-Jones, LN Smith (1994) 'Postoperative pain in children under five years' *Health Bull* 52, 193-195, referred to in Cleone Hart and Rosemary Chesson (1998) 'Children as consumers' *BMJ* 316, 1600-1603 (23 May), 1601.

176 R Bibace and M Walsh (1981) 'Children's conceptions of health, illness and bodily functions', San Francisco, CA; Jossey-Bass, referred to in Cleone Hart and Rosemary Chesson (1998) 'Children as consumers' *BMJ* 316, 1600-1603 (23 May), 1601.

177 Lois A Weithorn and Susan B Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98.

178 Any expression of choice, including waiver to an appropriate other to decide, earned one point on the 'Scale of Evidence of Choice': failure to indicate a preference resulted in a score of zero. Lois A Weithorn and Susan B Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, 1592.

179 A panel of 20 experts from paediatric and adolescent medicine and clinical child and adolescent psychology judged whether outcomes of decisions were reasonable. Experts were chosen to make the

judgments 'since, in reality, professional opinion is the criterion against which patients' preferences usually are measured for such determinations.' Lois A Weithorn and Susan B Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, 1592.

180 'On the Scale of Rational Reasons, one point could be earned … for providing each of several responses … to questions about what they had "considered," "thought about," or "taken into account" when making their decision.' Lois A. Weithorn and Susan B. Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, 1592.

181 The scale measuring understanding was composed of nine standardized questions foe each dilemma, designed to assess participants' understanding of the information disclosed in the dilemmas and their ability to make inferences about that information. Lois A. Weithorn and Susan B. Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, 1593.

182 Lois A. Weithorn and Susan B. Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, 1595-1596.

183 Lois A. Weithorn and Susan B. Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, 596.

184 See earlier discussion on p 11, notes 29-30, and see how members of the New Zealand judiciary have referred to *Gillick* in notes 58-66 to the discussion of cases on pp 14-15.

185 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 3, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

186 Concerns with restricting recognition of a minor's competence to situations in which they have exhibited a so-called 'rational' choice are discussed further below.

187 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, pp 3-4, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

188 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 14, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

189 Medical Council of New Zealand, *Information and Consent*, April 2002, cl 17, available from www.mcnz.org.nz/portals/1/Guidance/Information%20and%20Consent.pdf, accessed 21 June 2006.

190 Available at www.paediatrics.org.nz/PSNZold/disputes_03.html#1, accessed 21 June 2006.

191 [1992] 1 NZLR 363, 373.

192 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 93.

193 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, note 46.

194 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 567.

195 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 50, available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC, accessed on 20 June 2006.

196 J. Mansfield 'United Kingdom – Refusal of treatment (Child): Competence' (1997) 7 *Medical Law Review* 58.

197 Mairead Enright '"Mature" Minors and the Medical Law: Safety First?' [2004] *Cork Online Law Review* 6, p 5.

198 Lois A. Weithorn and Susan B. Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98.

199 Richard E. Redding (1993) 'Children's Competence to Provide Informed Consent for Mental Health Treatment' *Wash & Lee L. Rev.* 50, 695-754, 710.

200 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 87.

201 *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_03.html#1, accessed 21 June 2006.

202 Jeannie Bayly "Informed Consent and Paediatricians", accessed on 26 May 2006 from www.conferenz.co.nz/2004/library/b/bayly_jeannie.html.

203 *Re R (a minor)* [1991] 4 All ER 177, *Re W (A Minor)* [1992] 3 WLR 758, and *Re M (child: refusal of medical treatment)* [1999] 2 FCR 577, and *R v Laufau and Laufau* (High Court, Auckland, 23/8/00 and 2/10/00, T.000759.

204 *Re M (child: refusal of medical treatment)* [1999] 2 FCR 577.

205 *Re M (child: refusal of medical treatment)* [1999] 2 FCR 577, per Johnson J.

206 [1993] AC 789, 864 (HL).

207 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 558, citing *Airedale NHS Trust v Bland* [1993] AC 789, 864 (HL), per Lord Goff.

208 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 561-562.

209 Mairead Enright '"Mature" Minors and the Medical Law: Safety First?' [2004] COLR 6, p 2.

210 [1985] 3 All ER 402 (HL), at 423.

211 Andrew Bainham *Children: The Modern Law* (2nd Ed), Family Law, Bristol, 1998, p 278.

212 Peter S. Harper, Caron Lim, David Craufurd (2000) 'Ten years of presymptomatic testing for Huntington's disease: the experience of the UK Huntington's Disease Prediction Consortium' *J Med Genet.*2000; 37: 567-571: 'Although some studies done before testing became feasible suggested that uptake would be high (up to 80% per cent), this was not born out by subsequent experience, which has suggested levels of 5-20% per cent.' For these figures Harper et al refer to: D Craufurd, A Dodge, L Kerzin-Storrar, and R Harris R (1989) 'Uptake of presymptomatic predictive testing for Huntington's disease' *Lancet* 1989;ii:603-605, and A Tyler, D Ball, and D Craufurd (1992) 'Presymptomatic testing for Huntington's disease in the UK' *BMJ* 1992;304:1593-1596.z

213 Lois A Weithorn and Susan B Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98.

214 Alderson also suggests that competence means having the wisdom or discretion to evaluate information in the light of one's best interests. See Priscilla Alderson 'Talking to children – and talking with them,' pp 27-36, 33, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.

215 It is of course possible that a minor may become depressed or suicidal after receiving a mutation-positive test result, but the limited available evidence (discussed in the section on *Benefits and Harms)* suggests that such an outcome is unlikely. Additionally depression or suicide ideation could arise from an unwelcome result of medical testing for any serious or life-threatening illness.

216 Of course there may be circumstances in which a decision whether or not to undergo predictive genetic testing may be life-threatening: e.g. pre-symptomatic testing where a correct diagnosis could result in life-saving treatment. However, for some disorders, such as FAP, it may be more important to have other medical procedures (such as colonoscopies) than a predictive genetic test. In the case of surveillance for FAP, a predictive test without attendant colonoscopies (or prophylactic surgery) will not help prevent the onset of FAP, whereas colonoscopies without a predictive test would still be useful.

217 Priscilla Alderson 'Talking to children – and talking with them,' pp 27-36, 33, in Angus Clarke (1998) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.

218 See above discussion. It has been argued that from a cognitive perspective, competence in decision-making requires: the ability to process information logically; hypothetical and probabilistic reasoning about uncertain alternatives and outcomes; and having substantive knowledge about the area in which a decision is to be made. Hypothetical and probabilistic reasoning generally develops around the age of 11 years and is well-developed by 14 years. 'In terms of a cognitive, skills based understanding of competence, research evidence suggest that most people have achieved a reasonable level of competence in most of the core elements of decision making competence by the age of 15.' J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 915, referring to L. Mann, R. Harmoni, C. Power (1989) 'Adolescent decision-making: the development of competence' *J Adolescence* 12; 265-78. Also see Lois A. Weithorn and Susan B. Campbell (1982) 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' *Child Development* 53: 1589-98, Priscilla Alderson *Children's Consent to Surgery* Buckingham, Open University Press, 1993, and Susan Michie and Theresa M. Marteau (1996) 'Predictive genetic testing in children: The need for psychological research' *British Journal of Health Psychology* 1, 3-14. Joanna H. Fanos (1997) 'Developmental Tasks of Childhood and Adolescence: Implications for Genetic Testing' *Am J Med Genet* 71: 22-28, p 23: 'During adolescence there are considerable advances in cognitive abilities … making the intellectual understanding of testing procedures and results less problematic.'

219 Australian Institute of Family Studies (2006) 'Snapshots of Australian Families with Adolescents', Australian Government, accessed from www.aifs.gov.au/institute/pubs/snapshots/adolescents.pdf, on 9 August 2006. The study was put together for the 2006 National Families Week (14-20 May 2006).

220 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 916 referring to JR Korer and JS Fitzsimmons (1987) 'Huntington's chorea and the young person at risk' *Br J Social Wk* 17;521-34.

221 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 916.

222 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 916, referring to D.C. Wertz, J.H. Fanos, and P.R. Reilly (1994) 'Genetic Testing for children and adolescents: Who decides?' *JAMA* 1994; 272; 875-81.

223 D.C. Wertz, J.H. Fanos, and P.R. Reilly (1994) 'Genetic Testing for children and adolescents: Who decides?' *JAMA* 1994; 272; 875-81, 878.

224 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 915, referring to L. Mann, R. Harmoni, and C. Power (1989) 'Adolescent decision-making: the development of competence' *J Adolescence* 12; 265-78. Other research indicates that 14 and 15 year olds generally defer to perceived parental wishes in hypothetical medical decision-making. However, the degree of parental influence on medical decisions varies, and minors are more likely to resist parental influence when the consequences of the decision have serious implications for their health. J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 915, referring to D.G. Sherer and M.D. Reppucci (1988) 'Adolescents' Capacities to Provide Voluntary Informed Consent: The Effects of Parental Influence and Medical Dilemmas' *Law and Human Behaviour* 12; No 2; 123-141.

225 Donna L. Dickenson (1999) 'Can children and young people consent to be tested for adult onset genetic disorders' *BMJ* 318: 1063-1065, p 1064.

226 F.H. Richards (2006) 'Letter to the Editor in response to Duncan R.E. and Delatycki M.B. Predictive genetic testing in young people for adult-onset conditions: Where is the empirical evidence?' *Clin Genet* 69: 450-454, p 450.

227 F.H. Richards (2006) 'Letter to the Editor in response to Duncan R.E. and Delatycki M.B. Predictive genetic testing in young people for adult-onset conditions: Where is the empirical evidence?' *Clin Genet* 69: 450-454, p 450. Richards refers to L. Steinberg and E. Cauffman (1996) 'Maturity of Judgement in Adolescence: psychosocial factors in adolescent decision making' *Law Hum Behav* 20: 249-272, and E Cauffman and L Steinberg (2000) '(Im)aturity of judgement in adolescence: why adolescents may be less culpable than adults' *Behav Sci Law* 18: 741-760.

228 F.H. Richards (2006) 'Letter to the Editor in response to Duncan R.E. and Delatycki M.B. Predictive genetic testing in young people for adult-onset conditions: Where is the empirical evidence?' *Clin Genet* 69: 450-454, p 450. Richards refers to L. Steinberg and E. Cauffman (1996) 'Maturity of Judgement in Adolescence: psychosocial factors in adolescent decision making' *Law Hum Behav* 20: 249-272. In a subsequent paper (F.H. Richards (2006) 'Maturity of judgement in decision making for predictive testing for nontreatable adult-onset neurogenetic conditions: as case against predictive testing of minors' *Clin Genet* 70: 396-401), Richards refers to L. Steinberg and E. Cauffman (1996) 'Maturity of Judgement in Adolescence: psychosocial factors in adolescent decision making' *Law Hum Behav* 20: 249-272, E. Cauffman and L. Steinberg (2000) '(Im)maturity of judgement in adolescence: why adolescents may be less culpable than adults' *Behav Sci Law* 18: 741-760, N. Gogtay, J.N. Giedd, L. Lusk et al. (2004) 'Dynamic mapping of human cortical development during childhood through early adulthood' PNAS 101 (21) 8174-8179, and C.R. De Luca, S.J. Wood, V. Anderson et al. (2003) 'Normative data from the Cantab. I: development of executive function over the lifespan.' *J Clin Exp Neuropsychol* 25: 242-254. According to Richards (p 398) Steinberg and Cauffman found that 'psychosocial maturity continued to develop during mid-late adolescence, stabilizing after the age of 19 years. Younger adolescents scored lower on measures of self-reliance and other aspects of responsibility, had more difficulty perceiving the long-term perspective, and were more impulsive. It was concluded that this gradual development of psychosocial maturity has profound effects on the ability of adolescents to make consistently mature decisions. … Based on the findings of the study … adolescents younger than 18 years have not sufficiently developed these important aspects of psychosocial maturity, which are essential to predictive test decision making.' Richards (p 399) cites Gogtay et al for evidence that 'the prefrontal cortex, which is involved in executive function such as decision-making, continues to develop inb lat adolescence.' She also refers (p 399) to a study by De Luca et al which found that 'efficiency of the executive system improved in the late teens, … allowing cognitive processes to become more comprehensive, abstract and flexible in early adulthood' (p 250). … Decision-making in predictive testing for conditions such as HD is reliant on having adequate cerebral capacity to process information. Based on this evidence, adolescents are disadvantaged in their decision-making capacity by incomplete brain maturation and associated underdevelopment of executive functions.'

229 F.H. Richards (2006) 'Letter to the Editor in response to Duncan R.E. and Delatycki M.B. Predictive genetic testing in young people for adult-onset conditions: Where is the empirical evidence?' *Clin Genet* 69: 450-454, p 450. In light of that statement, Semaka aptly suggests that it would seem likely that Richards would support a competence assessment approach to testing rather than a strict age-based approach: A Semaka (2006) 'Response to Fiona Richards' 'Letter to the Editor" *Clin Genet* 69: 452-453, p 452. Richards responds that she considers that testing from the age of 18 years may or may not go ahead according to factors such as maturity, whereas testing under the age of 18 years should not go ahead: FH Richards (2006) 'Response to Semaka' *Clin Genet* 69: 453-454, p 453. She approves of a competence based assessment only for persons over the arbitrary cut-off age of 18 years.

230 Angus Clarke 'The Genetic Testing of Children,' pp 231-247, 237, in Ruth Chadwick, Darren Shickle, Henk Ten Have and Urban Wiesing *The Ethics of Genetic Screening* Kluwer Academic Publishers, Dordrecht, 1999.

231 Gail Geller (1999) 'Commentary: Weighing burdens and benefits rather than competence' *BMJ* 318: 1065-1066, p 1066.
232 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 913.
233 Clinical Genetics Society (UK) (1994) 'The Genetic Testing of Children, Report of a Working Party of the Clinical Genetics Society, Chaired by Dr Angus Clarke' J *Med Genet* 1994; 31; 785-797, 791.
234 D.C. Wertz, J.H. Fanos, and P.R. Reilly (1994) 'Genetic Testing for children and adolescents: Who decides?' *JAMA* 1994; 272; 875-81, 877.
235 Timothy Caulfield (1997) 'Testing Adolescents for the Alzheimer Gene: Tensions in Law and Policy' 25 *Man. L.J.* 31.
236 See note 133.
237 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC gives the following examples of exceptions to the general requirement to obtain informed consent (p 15): '(a) In emergencies, where an appropriate person cannot be found to give consent, health care professionals can – and have an obligation to – provide relevant treatment (common law and Crimes Act 1961). (b) Blood transfusions can be administered to children without consent in certain circumstances (s. 126B Health Act 1956). (c) Some legislation allows for compulsory treatment, for example the Mental Health (Compulsory Assessment and Treatment) Act 1992. The Health Act 1956 and the Tuberculosis Act 1994 also contain provisions for compulsory examinations and treatment. (d) In situations where a person of any age (including children and young people) is suspected of having excess blood alcohol levels, blood specimens may be taken by a registered medical practitioner or 'authorised person' without consent if required by an 'enforcement officer' (Transport Act 1962).'
238 See earlier discussion on p 11, notes 29-30, and see how members of the New Zealand judiciary have referred to *Gillick* in notes 58-66 to the discussion of cases on pp 14-15.
239 Timothy Caulfield (1997) 'Testing Adolescents for the Alzheimer Gene: Tensions in Law and Policy' 25 *Man. L.J.* 31, p 43.
240 J Binedell, JR Soldan, J Scourfield, and PS Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 916-917.
241 Except, obviously, in terms of clinical priorities: if some people have greater medical indications for testing, regardless of their age, and resources are limited, their requests should be favoured over those for whom testing is not clinically indicated.
242 Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005, p 48, (accessed from http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf, on 17 September 2006): quote from a 20 year old female who was tested (and found negative) for the HD mutation at the age of 18 years.
243 Phillipa J Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl.
244 Priscilla Alderson 'Talking to children – and talking with them,' pp 27-36, 34, in Angus Clarke (1998) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.
245 FH Richards (2006) 'Maturity of judgement in decision making for predictive testing for nontreatable adult-onset neurogenetic conditions: as case against predictive testing of minors' *Clin Genet* 70: 396-401, pp 398-399.
246 D.C. Wertz, J.H. Fanos, and P.R. Reilly (1994) 'Genetic Testing for children and adolescents: Who decides?' *JAMA* 1994; 272; 875-81, 879.
247 M. Cappelli, S. Verma, Y. Korneluk, A. Hunter, E.V. Tomiak, J. Allanson, C. DeGrasse, L. Corsini and

L. Humphreys (2005) 'Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer' *Clin Genet* 67: 481-491.

248 M. Cappelli, S. Verma, Y. Korneluk, A. Hunter, E.V. Tomiak, J. Allanson, C. DeGrasse, L. Corsini and L. Humphreys (2005) 'Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer' *Clin Genet* 67: 481-491, 487.

249 They also reported perceived benefits of genetic testing, including test results helping them to make decisions regarding screening, and potential changes to lifestyle as a preventive strategy. M. Cappelli, S. Verma, Y. Korneluk, A. Hunter, E.V. Tomiak, J. Allanson, C. DeGrasse, L. Corsini and L. Humphreys (2005) 'Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer' *Clin Genet* 67: 481-491, 487-489.

250 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 916.

251 Joanna H. Fanos (1997) 'Developmental Tasks of Childhood and Adolescence: Implications for Genetic Testing' *Am J Med Genet* 71: 22-28, p 27.

252 Priscilla Alderson 'Talking to children – and talking with them,' pp 27-36, 35, in Angus Clarke (1998) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.

253 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8.

254 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 915.

255 Nathaniel H. Robin (2004) 'Genetic testing will bring interesting times to clinical practice' *Current Opinion in Paediatrics* 16: 667-669, 667.

256 Brynn K. Wainstein, Katy Sterling-Levis, Sally A. Baker, Jonathon Taitz, and Michael Byrdon (2006) 'Use of the Internet by parents of paediatric patients' *Journal of Paediatrics and Child Health* 42, 528-532, 530, referring to T. Kind, Z.J. Huang, D. Farr, and K.L. Pomerantz (2005) 'Internet and computer access and use for health information in an underserved community' *Ambul Pediatr* 5, 117-21, and S. Dickerson, A.M. Reinhart, T.H. Feeley et al (2004) 'Patient internet use for health information at three urban primary care clinics' *J. Am. Med. Inform. Assoc.* 11; 499-504.

257 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' J Med Genet 1996;33(11):912-8, 914.

258 Human Genetics Society of Australasia Policy *Predictive Testing in Children and Adolescents*, Version 2, April 2005. Accessed on 8 May 2006 from http://hgsa.com.au/images/UserFiles/Attachments/Predictivetesting(General)APRIL2005.pdf.

259 *Paediatrics and Child Health* Vol. 8 No. 1 January 2003, 42-45, p 43-44. The Position Statement refers to J.H. Fanos (1997) 'Developmental tasks of childhood and adolescence: Implications for genetic testing,' *Am J Med Genet* 1997; 71:22-28. The doctrine of 'assent' is discussed in the section on minors who cannot give informed consent, as the focus in this section is minors who may be considered competent to give informed consent.

260 Canadian Paediatric Society, Position Statement (B 2003 – 01) 'Guidelines for genetic testing of healthy children,' in *Paediatrics and Child Health* Vol 8 No 1 January 2003, 42-45, 44. The Statement references: A Farakas-Patenaude (1996) 'The Genetic testing of children for cancer susceptibility: Ethical, legal and social issues.' *Behav Sci Law* 1996;14;393-410, and MA McCabe (1996) 'Involving children and adolescents in medical decision-making: Developmental and clinical considerations.' *J Pediatr Psychology* 1996: 21: 505-16.

261 American Society of Human Genetics/American College of Medical Genetics Report, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents,* 1995, accessed from www.ashg.org/genetics/ashg/pubs/policy/pol-13.htm, 8 May 2006. The Report refers to the Federal Regulation 45 CFR 46.406, 1994. Also, refer to note 261.

262 American Society of Human Genetics/American College of Medical Genetics Report, *Points to*

Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents, 1995, Point 5 – Points to Consider, accessed from www.ashg.org/genetics/ashg/pubs/policy/pol-13.htm, 8 May 2006.

263 American Society of Human Genetics/American College of Medical Genetics Report, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents,* 1995, accessed from www.ashg.org/genetics/ashg/pubs/policy/pol-13.htm, 8 May 2006. The Report refers to AK Buchanan and DW Brock *Deciding for others: the ethics of surrogate decision-making.* Cambridge University Press, Cambridge, 1989.

264 American Society of Human Genetics/American College of Medical Genetics Report, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents,* 1995, accessed from www.ashg.org/genetics/ashg/pubs/policy/pol-13.htm, 8 May 2006. The Report refers to W.J. Wadlington 'Consent to medical care for minors: the legal framework,' and L.A. Weithorn 'Involving children in decisions affecting their own welfare: guidelines for professionals,' both in GB Melton, GPO Knocher, MJ Saks (Eds) *Children's competence to consent.* Plenum Press, New York and London, 1983, pp 57-74 and pp 235-260.

265 See sections headed Professional Guidelines and Position Papers in Respect of Genetic Testing of Minors and Attitudes and Professional Practice Regarding Genetic Testing of Minors for further discussion.

266 *Consent in Child and Youth Health* Ministry of Health, Wellington, 1998, p 24, accessed on 20 June 2006 from http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.

267 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 564.

268 Morag McDowell (1997) 'Medical Treatment and Children: Assessing the Scope of a Child's Capacity to Consent or Refuse to Consent in New Zealand' *Journal of Law and Medicine* 5, August 1997, 81-96, 94-95. McDowell also notes that judges also risk underestimating the maturity of children when making medical decisions, particularly if their decision differs from that which the judge would want to make.

269 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 561.

270 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 562.

271 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 562.

272 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 571. McLean refers to comments from one GP to the effect that it is a distinct advantage to understand the family background and that it is 'much more difficult if you don't know the family.'

273 Alice Christian (2005) 'In the Spotlight – Genetic Services' *Parent 2 Parent Newsletter,* March 2005, p 6, accessed from www.parent2parent.org.nz/news/March_2005.pdf 19 October 2006.

274 Human Genetics Society of Australasia Policy, *Presymptomatic and Predictive Testing for Genetic Disorders* 2005, Version 2, April 2005, p 2. Accessed on 16 May 2006 from http://hgsa.com.au/images/UserFiles/Attachments/PresymptomaticandPredictiveTestingforGeneticDisordersV22005.pdf.

275 HGSA (2002) *Guidelines for Human Genetics Society of Australasia (HGSA) Training and Certification in Genetic Counselling,* accessed on 30 January 2007 from http://hgsa.com.au/images/UserFiles/Attachments/CombinedsectionsofguidelinesApril2002RevisedJuly042.pdf.

276 Human Genetics Society of Australasia Policy, *Presymptomatic and Predictive Testing for Genetic Disorders* 2005, Version 2, April 2005, pp 2-3. Accessed on 16 May 2006 from http://hgsa.com.au/images/UserFiles/Attachments/PresymptomaticandPredictiveTestingforGeneticDisordersV22005.pdf.

277 *Disagreements between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_03.html, accessed 21 June 2006. The ASHG/ACMG Report (American Society of Human Genetics/American College of Medical Genetics Report, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents,* 1995, accessed from www.ashg.org/genetics/ashg/pubs/policy/pol-13.htm, 8 May 2006) also propounds the utility of consulting with other providers (including ethics committees) in order to evaluate harms and benefits, decision-making capacity and voluntariness (p 6, online version).

278 J. Binedell, J.R. Soldan, J. Scourfield, and P.S. Harper (1996) 'Huntington's disease predictive testing: the case for an assessment approach to requests from adolescents.' *J Med Genet* 1996;33(11):912-8, 916.

279 Kathryn McLean (2000) 'Children and Competence to Consent to Medical Treatment' *Victoria U. Wellington L. Rev.* 31, 551 – 576, 564. McLean suggests that an objective standard to assessing competence, requiring doctors to make their decision as the 'reasonable doctor' would do so, would be too strict. However, an entirely subjective approach to assessing competence risks making the decision 'unquestionable and untouchable.' She suggests that a more appropriate standard might be that of procedural fairness: a fair procedure must be followed and 'the decision arrived at must not be so wholly unreasonable that no reasonable doctor could have made it.' (p 562).

280 Vic Larcher (2005) 'Consent, competence, and confidentiality' *BMJ* 330, 353-356, 355.

281 D.C. Wertz, J.H. Fanos, and P.R. Reilly (1994) 'Genetic Testing for children and adolescents: Who decides?' *JAMA* 1994; 272; 875-81, 879.

282 Harper, Glew, and Harper note: 'This paper, with the subsequent widespread discussion at British and European genetics meeting, contributed to the evolution of practice and policies from the more rigid original guidelines.' Peter Harper, Ruth Glew, Ruth Harper (1999) 'Letter to the Editor, Response to requests for genetic testing is not based on age alone' *BMJ* 319, 578.

283 Julia Binedell 'Adolescent requests for predictive genetic testing,' pp 123-132, 130, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.

284 Julia Binedell 'Adolescent requests for predictive genetic testing,' pp 123-132, 130, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.

285 Julia Binedell 'Adolescent requests for predictive genetic testing,' pp 123-132, 130, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998, and see note 1.

286 Sharpe et al. (1993) 'Letter to the Editor: Presymptomatic Testing for Huntington Disease: Is There a Duty to Test Those Under the Age of Eighteen Years?' *American Journal of Medical Genetics* 46:250-253, 251.